

AM Testimony
Pages 29-96

I'M THE ACTING ASSISTANT SECRETARY FOR THE OFFICE OF FAIR

HOUSING AND EQUAL OPPORTUNITY, UNITED STATES DEPARTMENT OF
HOUSING AND URBAN DEVELOPMENT.

>> PLEASE.

>> HI, I'M BOB PASTERNAK.

I'M THE ASSISTANT SECRETARY FOR THE OFFICE OF SPECIAL
EDUCATION

AND REHABILITATIVE SERVICES AT THE U.S. DEPARTMENT OF
EDUCATION.

>> I'D LIKE TO CLOSE AND MOVE OUT OF THE WAY AND MOVE TO THE
TESTIMONY BY THANKING ALL OF YOU FOR COMING TODAY, FOR
TAKING

TIME OUT OF YOUR BUSINESS SCHEDULE TO PARTICIPATE IN WHAT I
HOPE
IS GOING TO BE A VERY INFORMATIVE AND VERY USEFUL SESSION.
AND WITH THAT, MR. CLARK, IF I CAN TURN TO YOU TO BEGIN THE
TESTIMONY, PLEASE.

>> THANK YOU.

MY NAME IS MICHAEL CLARK.

I COME UP FROM BRUNSWICK, GEORGIA.

I WAS BORN AND RAISED HERE IN WASHINGTON, D.C.

I HAD MY NECK BROKE SEVEN YEARS AGO WHEN I WAS HIT BY A CAR.

I FOUND OUT I WAS ALSO H.I.V. POSITIVE SEVERAL YEARS LATER
WHEN

I WAS SEEKING SOME HELP FOR DEPRESSION IN THE MENTAL WARD,
SO I

WAS IN THE RIGHT PLACE AT THE RIGHT TIME WHEN I RECEIVED
THAT

NEWS.

SINCE I HAVE BEEN IN BRUNSWICK, I MOVED OUT -- I'VE BEEN
THERE

FOR ABOUT THREE YEARS NOW.

I'M AFFILIATED WITH PARTNERS AND POLICY MAKING, A PROGRAM
CALLED

THE STAR FOUNDATION AND THE COASTAL AREA SUPPORT TEAM.

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THE STAR FOUNDATION WORKS WITH THE HOUSING AUTHORITY OF
BRUNSWICK AND WE PROVIDE FREE COMPUTER TRAINING FOR THE
RESIDENTS AND WE TRY TO FIND THEM JOBS.

I WAS ALSO ASKED TO SIT ON THEIR BOARD OF DIRECTORS AND I
SIT ON

THE CASH BOARD OF DIRECTORS.

THE COASTAL AREA SUPPORT TEAM WORKS WITH PEOPLE AND FAMILIES
WHO
ARE H.I.V. AND AIDS.

WHAT I DO THERE IS I GO TO THE HIGH SCHOOLS AND I TALK TO
THE

KIDS ABOUT H.I.V. AND AIDS AND HOW NOT TO GET IT.

AND I PRESENT IT TO THEM IN A REAL WAY AND HOW IT REALLY IS
IN
LIFE.

AND FROM WHAT I HAVE SEEN, THE RESULTS HAVE BEEN PRETTY
GOOD.

I HAD A LADY APPROACH ME WHO WAS A PASTOR AT A CHURCH WHILE
I

WAS IN THE THRIFT STORE AND SHE TOLD ME HER DAUGHTER HEARD
ME

SPEAK AT THE HIGH SCHOOL AND SHE CAME HOME AND SAID, MOM, I
AM

NOT HAVING SEX UNTIL I GET MARRIED AND THEN WE WILL BOTH BE
TESTED.

SO I KNOW THAT'S MAKING AN IMPACT.

I BELIEVE -- MY THEORY IS AN OUNCE OF PREVENTION IS WORTH A

YOU POUND OF CURE, BECAUSE IF YOU CAN PREVENT CERTAIN THINGS,
AIN'T GOT TO WORRY ABOUT CURING THEM.
NOW, I WANTED TO SAY SOMETHING ABOUT MEDICAID BECAUSE THEY
ARE PRESCRIBING H.I.V. MEDICATION FOR WEIGHT GAIN.
IT'S CALLED AXANDRIN.
AND THE PRESCRIPTION, THE INSURANCE PAYS \$838 A MONTH FOR
THESE PILLS.

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THERAPY AND MY RECOMMENDATION IS IF A PATIENT HAS AN ALTERNATIVE
DOCTOR AND IT'S CHEAPER THAN WHAT MEDICAID IS PAYING FOR AND THE
AGREES UPON IT, I THINK WE SHOULD GO WITH THAT BECAUSE I WAS
NUTRITION DRINKING SOME OF THOSE PROTEIN SHAKES FROM THE GENERAL
THEY CENTER, WHICH WAS COSTING ME MAYBE \$60 A MONTH AT MOST, AND
CAN TAKE THE REST OF THAT MONEY, MAN, AND PUT IT INTO SOME
EDUCATION OR SOME PROGRAMS FOR PEOPLE WITH DISABILITIES.
THAT'S WHAT I'M THINKING, YOU KNOW, THAT'S JUST MY
RECOMMENDATION.
AND IF I CAN GET MY THOUGHTS RIGHT.
HOLD ON FOR A MINUTE.
I LOST MY TRAIN OF THOUGHT.
BUT ANYWAY, I GOT TO SUM IT UP.
AND MY RECOMMENDATION IS WE CAN SAVE MONEY THAT WAY.
BUT THE COASTAL AREA SUPPORT TEAM AND THESE RURAL AREAS, THE

THING THAT I FOUND WE NEED IT MOST, I DID A SURVEY, WE DON'T
HAVE ENOUGH TRANSPORTATION.

TO
IF YOU CAN GET US JUST A COUPLE OF VANS, WE CAN ACTUALLY GET
BRING
THESE PEOPLE AND MAKE A REALLY BIG DIFFERENCE AND WE CAN
THEM TO THE SERVICES WHERE THEY NEED TO GET TO AND I GOT TO
CLOSE IT OUT.

THANK YOU.

>> THANK YOU, MR. CLARK.

PLEASE, MA'AM?

PEOPLE
>> MY NAME IS JACKIE MCKINNEY, AND I AM WITH THE NATIONAL
OF COLOR CONSUMER SURVIVOR NETWORK.

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ILLNESS.
AND I AM A PERSON WHO HAS BEEN DIAGNOSED WITH MENTAL

FAMILY
I WOULD JUST LIKE TO INTRODUCE NOT JUST MYSELF, BUT MY
WHO COULDN'T BE HERE.

EXPERT
LIKE MOST CONSUMERS OF MENTAL HEALTH SERVICES, I AM THE
ON MY OWN ILLNESS.

IN ADDITION, I REPRESENT MY FAMILY WHO HAVE SIX LIVING
GENERATIONS.

I CURRENTLY LIVE WITH MY MOTHER WHO HAS ADVANCED ALZHEIMER'S
DISEASE AND REQUIRES 24-HOUR CARE.

MY CHILDREN RANGE IN AGE FROM 35 TO 51.

IN
AND SINCE MY ILLNESS HAD ITS ONSET DUE TO VIOLENCE AND ABUSE
MY EARLY CHILDHOOD, WE, THE CHILDREN AND I HAVE LIVED WITH

MENTAL HEALTH ISSUES OUR ENTIRE LIVES.
AS A RESULT, WE HAVE EXPERIENCED, AS MANY AFRICAN AMERICANS
HAVE, LIFE AS PEOPLE WITH MULTIPLE VULNERABILITIES.
AND WE HAVE HAD A GREATER EXPOSURE TO RACISM,
DISCRIMINATION,
VIOLENCE, AND POVERTY.
AND RACISM AND DISCRIMINATION HAVE ADVERSELY AFFECTED NOT
JUST
OUR MENTAL HEALTH, BUT OUR HEALTH.
BECAUSE I BELIEVE THAT THE MIND AND THE BODY ARE
INSEPARABLE.
FOR THE LAST SEVEN YEARS, I HAVE LIVED WITH EIGHT OF MY
GRANDCHILDREN, DUE TO THEIR PARENTS BEING HOMELESS,
INCARCERATED
AND INSTITUTIONALIZED.
ADD TO THIS FORMULA OF FAILURE, THE RAGE AND THE ANGER THAT
HAS
OCCURRING
BECOME THEIR HERITAGE AS THEY LIVE WITH UNTREATED CO-
DISORDERS.

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MY GRANDCHILDREN, LIKE MANY AFRICAN AMERICAN CHILDREN, HAVE
LIVED WITH FOSTER CARE PLACEMENTS -- AS MANY AS 16 FOR TWO
OF
THEM.
AND IN THOSE PLACEMENTS, THEY HAVE LIVED WITH THE CYCLE
AGAIN OF
ABUSE AND VIOLENCE BECAUSE IT WAS CONTINUED.
HOMELESSNESS HAS BEEN THEIR PLIGHT, SHELTERS HAVE BEEN THEIR
FLIGHT AND FEAR FOR THEIR ENTIRE LIVES.
ALL OF US FOR CONSUMERS, WE ARE ALL CONSUMERS.

SOME OF SERVICES AND SOME OF RAGE.

FROM YOUR AGENCIES WHAT I WOULD SAY TO YOU PARTICULARLY ARE
PROBABLY THREE WORDS.

I WOULD LIKE TO TALK A TINY BIT ABOUT DISPARITIES.

AFRICAN AMERICANS HAVE PROVEN TO HAVE LESS THAN ONE PERCENT
OF

THE RESOURCES EVEN THAT LITTLE BIT THAT'S GIVEN TO THE
CONSUMER

MOVEMENT.

WE RUN NOTHING, WE HAVE NOTHING AND WE ARE NOT PROVIDED THE
NECESSARY TECHNICAL ASSISTANCE THAT OUR NUMBERS WARRANT.

THERE ARE TWO NATIONAL RESEARCH STUDIES THAT I AM A PART OF
--

ACTUALLY, I DO A LOT OF WORK FOR A PERSON MY AGE AND STAGE,
BUT

IT'S FUELED NO LONGER BY ANGER, BUT BY INTEREST.

I WANT TO SAY THAT OVER AND OVER.

THAT OPPORTUNITIES HAVE BEEN GIVEN TO ME THAT HAVE CHANGED
ME

FROM THE RAGING WOMAN THAT I WAS WHEN I ENTERED -- AND

RIGHTFULLY SO -- ENTERED THIS MOVEMENT AND HAVE MADE ME WANT
TO

COME TODAY TO SAY ONE MORE THING.

I WANT TO HOLD UP THIS BOOK BECAUSE THIS IS WHAT I AM GOING
TO

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BE DOING FOR THE REST OF MY LIFE.

THIS IS THE SURGEON GENERAL'S COPY OF RACE, MENTAL HEALTH,
CULTURE, RACE AND ETHNICITY.

WHY DO I HOLD THIS UP?

MENTAL BECAUSE I BELIEVE THAT'S WHAT'S MISSING FOR PEOPLE WITH
A HEALTH DIAGNOSIS IS AN OPPORTUNITY TO HAVE A REAL DIALOGUE,
AND DIALOGUE WITH THE PEOPLE JUST LIKE YOU IN THE FRONT OF ROOM
IN THE BACK OF THE ROOM.
I DON'T THINK THE BOOK WILL DO WHAT NEEDS TO BE DONE, BUT
WHAT I THINK THE BOOK WILL DO WILL GIVE US IN A SENSITIVE AND
KNOWLEDGEABLE WAY INFORMATION SO WE CAN BEGIN A DIALOGUE.
I HAVE WAITED MY WHOLE LIFE TO HAVE AN OPPORTUNITY TO HAVE
PARITY.
SPEAK IF I BELIEVE AT LEAST WE WILL HAVE PARITY WHEN WE START TO
WE WILL READ THIS BOOK.
I DON'T KNOW THE SURGEON GENERAL PERSONALLY.
HE'S NEVER PAID ME A DIME.
AND I'M JUST SO GRATEFUL THAT SOMEONE CREATED AN ENCYCLOPEDIA SO
THAT BLACK PEOPLE AND WHITE PEOPLE AND PEOPLE OF ALL COLORS
KINDS CAN HAVE A COMMON LANGUAGE.
WE BECAUSE I KNOW WHEN YOU START TO TALKING WITH ONE ANOTHER,
ISSUES. ARE GOING TO REALLY FIND THAT WE CAN SOLVE SOME OF THE
DON'T AND I WON'T GIVE YOU A STREAM OF RECOMMENDATIONS BECAUSE I
HAVE ANY.
BUT I DO RECOMMEND THAT YOU READ THIS BOOK.
THANK YOU.

>> THANK YOU, MS. MCKINNEY.

PLEASE?

>> MY NAME IS JOHN BROCK.

I AM A MEMBER OF THE CENTER MENTAL HEALTH SERVICES
SUBCOMMITTEE

ON CONSUMER AND SURVIVOR ISSUES.

THE NEW FREEDOM INITIATIVE PROPOSES A NATIONAL COMMISSION ON
MENTAL HEALTH, A RETHINKING OF FEDERAL POLICY ABOUT MENTAL
HEALTH ISSUES.

INCLUDE
IT IS IMPAIRTIVE THAT THE PROPOSED NATIONAL COMMISSION

PEOPLE
CONSUMERS AND SURVIVORS OF PUBLIC MENTAL HEALTH SERVICES,

WHO HAVE EXPERIENCED MENTAL ILLNESS, TREATMENT AND RECOVERY.

WOULD
IN THIS ROOM, WHO WOULD IMAGINE THE AMERICAN GOVERNMENT

CREATE A NATIONAL COMMISSION TO CHANGE FEDERAL POLICY ABOUT
RACE, COLOR, SEX, AGE, RELIGION AND YET HAVE NO AFFECTED
CITIZENS PARTICIPATE ON SUCH A COMMISSION?

TIME
IN MENTAL HEALTH AS IN OTHER AREAS OF AMERICAN LIFE, IT IS

TO TALK WITH THE PEOPLE WE HAVE BEEN TALKING ABOUT.

LOCAL
THE STANDARDS SET BY THE FEDERAL GOVERNMENT FOR STATE AND

MENTAL HEALTH PLANNING COUNCILS IS THAT AT LEAST HALF THEIR
MEMBERS BE CONSUMERS AND SURVIVORS OF PUBLIC HEALTH MENTAL
SERVICES.

HAVING AT
THE FEDERAL GOVERNMENT SHOULD MEET ITS OWN STANDARD BY

CONSUMERS
LEAST HALF THE NATIONAL COMMISSION ON MENTAL HEALTH BE

AND SURVIVORS.

HAVE

CONSUMERS AND SURVIVORS OF PUBLIC MENTAL HEALTH SERVICES

EARNED A PLACE AT THE FEDERAL POLICY-MAKING TABLE.

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HEALTH

WE NOW PARTICIPATE IN STATE LEVEL AND LOCAL LEVEL, MENTAL

POLICY MAKING BOARDS IN EVERY STATE AND THOUSANDS OF LOCAL
COMMUNITIES.

WE NOW ALLY WITH FUNDERS AND PROVIDERS AT FEDERAL AND
INTERNATIONAL LEVELS.

EXPRESSED BY
IF ANY AMERICAN CITIZENS DO COMMUNITY LEVEL WORK AS

OF
PRESIDENT BUSH IN HIS POLICY STATEMENT, RALLYING THE ARMIES

COMPASSION, IT IS CONSUMER SURVIOR MOVEMENT PARTICIPANTS.

STRUGGLING TO
WE WHO EXPERIENCE MENTAL ILLNESS AND TREATMENT ARE

RECLAIM OUR HUMANITY, OUR CITIZENRY, OUR LIVES, OUR ROLES AS
PARENTS, PROVIDERS, CONTRIBUTING MEMBERS OF THE LARGER
COMMUNITY.

WE SEE TRADITIONAL MENTAL HEALTH PROGRAMS AS REDISTRIBUTED
PROGRAMS THAT FOCUS ON MAINTENANCE, DIAGNOSIS, FORCE, DRUGS,
DEPENDENCY.

ON
WE SEE OUR INNOVATIVE CONSUMER SURVIVOR PROGRAMS AS FOCUSING

PERSON, CHARACTER, CHOICE, HUMAN CAPACITY AND POSSIBILITY.

TO
OUR GRASS ROOT DEVELOPMENTAL PROGRAMS ARE INCREASINGLY READY

COMPETE WITH, SUPPLEMENT, OR REPLACE MANY TRADITIONAL
REDISTRIBUTED MENTAL HEALTH PROGRAMS.

WE ARE INCREASINGLY READY FOR FEDERAL AND STATE FUNDING.

CONSUMERS OF PUBLIC MENTAL HEALTH SERVICES ARE INCREASINGLY
READY FOR A CHOICE.

HEALTH
AGAIN, IT IS IMPAIRTIVE THE NATIONAL COMMISSION ON MENTAL
INCLUDE AT LEAST HALF ITS NUMBERS BE PEOPLE WHO HAVE
EXPERIENCED
MENTAL ILLNESS, TREATMENT, AND RECOVERY.

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IT IS TIME TO REFORM THE ECONOMIC MONOPOLY OF TRADITIONAL
REDISTRIBUTIVE MENTAL HEALTH POLICY THROUGH GREATER USE OF
DEVELOPMENTAL, MENTAL HEALTH POLICY.

TIME
IN MENTAL HEALTH, AS IN OTHER AREAS OF AMERICAN LIFE, IT IS

TO TALK WITH THE PEOPLE WE HAVE BEEN TALKING ABOUT.

>> THANK YOU, MR. BROCK.

MR. ABRAMS?

>> GOOD MORNING.

MY NAME IS RICK ABRAMS.

I'M CHIEF OPERATING OFFICER OF THE AMERICAN HEALTH CARE
ASSOCIATION.

12,000
WE ARE A NATIONAL TRADE ASSOCIATION, REPRESENTING OVER
FACILITY-BASED -- LONG-TERM CARE FACILITIES SUCH AS NURSING
FACILITIES, ASSISTED LIVING RESIDENTS, RESIDENTS THAT CARE
FOR

FOLKS WITH MENTAL RETARDATION AND DEVELOPMENTAL
DISABILITIES.

IN
AND I WANT TO THANK YOU FOR THE OPPORTUNITY TO PARTICIPATE

THIS SESSION TODAY.

WE HAVE ALREADY SUBMITTED WRITTEN COMMENTS FOR THE RECORD.

I DO HAVE ADDITIONAL COPIES WITH ME.

MY PURPOSE FOR BEING HERE TODAY AND TO PARTICIPATE IN THIS SESSION IS REALLY TO EMPHASIZE SIX POINTS.

FIRST, THE AMERICAN HEALTH CARE ASSOCIATION AS REPRESENTATIVE OF

FACILITY-BASED PROVIDERS IS VERY, VERY SUPPORTIVE OF CHOICE FOR

THE ELDERLY AND PEOPLE WITH DISABILITIES IN THIS COUNTRY.

AND WE WANT TO WORK TOWARD THAT GOAL.

SECONDLY, AND REALLY THIS IS A LINK TO POINT ONE, IT'S

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CRITICALLY IMPORTANT THAT THE PUBLIC BOTH CLIENTS, PATIENTS, RESIDENTS, THEIR LOVED ONES AS WELL AS PROVIDERS BE EDUCATED AS

TO THE CONTINUUM OF LONG-TERM CARE OPPORTUNITIES THAT ARE AVAILABLE TO PEOPLE FROM SUB ACUTE OR SKILLED NURSING FACILITIES

TO HOME-BASED CARE.

THIRDLY, CRITICALLY IMPORTANT AGAIN, THAT THE FRAIL ELDERLY AS

WELL AS THE DISABLED HAVE PLACEMENT IN THE LEAST RESTRICTIVE,

MOST APPROPRIATE AND MOST COST-EFFECTIVE SETTING AND THE AMERICAN HEALTH CARE ASSOCIATION IS COMMITTED TO WORKING WITH

BOTH GOVERNMENT OFFICIALS, CONSUMER ADVOCATES, AND PATIENTS TO

ACHIEVE THAT GOAL.

FOURTHLY, WE SUPPORT A BALANCED, LONG-TERM CARE CONTINUUM.

AND WHAT I MEAN BY THAT IS THAT THAT WE SUPPORT PROVIDING FOLKS

SERVICES WITH THE OPTIMUM OF ACCESS, PROTECTION AS WELL AS REASONABLE REIMBURSEMENT TO ALL PROVIDERS FOR THE INDISPENSABLE

THAT THEY PROVIDE.

ROBBING FIFTHLY, THE AMERICAN HEALTH CARE ASSOCIATION OPPOSES

PETER TO PAY PAUL.

ONE BY THAT I MEAN ARBITRARILY MOVING FUNDING AND RESOURCES FROM

COMPONENT COMPONENT OF THE LONG-TERM CARE CONTINUUM TO ANOTHER

WITHOUT FIRST ASSESSING BOTH PRESENT AND FUTURE NEED.

AND ALSO THE IMPACT OF REMOVING THAT FUNDING TO BOTH THE PATIENTS AND THE PROVIDERS.

IN THE OTHER PART OF THE CONTINUUM.

OPENED AND FINALLY, I WANT TO CLOSE IN THE SAME MANNER THAT I

THE AND THAT IS IS THAT IN ORDER TO SOLVE THE ISSUES AND ADDRESS

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IT ISSUES THAT AFFECT THE ELDERLY AND DISABLED IN THIS COUNTRY,

PROBLEM, IS NOT JUST THE PROVIDER'S PROBLEM, NOR GOVERNMENT'S

NOR PATIENT'S PROBLEMS, NOR CONSUMER ADVOCATES PROBLEMS, IT IS ALL OF OUR RESPONSIBILITIES.

CARE AND, AGAIN, WHAT I WANT TO SAY IS THAT THE AMERICAN HEALTH

WORK ASSOCIATION STANDS READY TO WORK WITH ALL WHO WOULD LIKE TO

FACE ON THIS VERY, VERY IMPORTANT ISSUE AND PROBLEMS INDEED THAT

YOUR NATION.

AGAIN, THANK YOU VERY MUCH FOR ALLOWING ME ON BEHALF OF THE
AMERICAN HEALTH CARE ASSOCIATION TO PARTICIPATE IN THIS
SESSION.

THANK YOU.

>> MR. ABRAMS, THANK YOU.

MS. KNISLEY, BEFORE WE GO TO YOU, I WOULD LIKE TO DO TWO
THINGS,

PLEASE.

FIRST OF ALL, I'D LIKE TO THANK ALL FOUR INDIVIDUALS WHO
PROVIDED TESTIMONY AT THIS POINT.

I THINK WE WILL HAVE THE NEXT GROUP OF FOUR COME DOWN.

WE THANK YOU.

I ALSO KNOW THAT WE HAVE HAD SOMEONE JOIN US AT THE PODIUM
AND I

WOULD LIKE TO GIVE HIM THE OPPORTUNITY TO INTRODUCE HIMSELF.

MR. BOYD?

>> THANK YOU VERY MUCH.

THANK YOU VERY MUCH, MR. BARTLETT.

THANK ALL OF YOU.

I AM DELIGHTED TO BE HERE TODAY AS THE NEWLY MINTED
ASSISTANT

ATTORNEY GENERAL FOR CIVIL RIGHTS AND BEING HERE TODAY TO

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PARTICIPATE IN THIS VERY, VERY IMPORTANT LISTENING SESSION
RELATED TO THE NEW FREEDOM INITIATIVE AS ONE OF MY EARLY
OFFICIAL ACTS AS THE NEW ASSISTANT ATTORNEY GENERAL FOR
CIVIL

RIGHTS AND I COULDN'T BE MORE DELIGHTED TO BE HERE.

REGRETS

AND I WANT TO TELL YOU THAT ATTORNEY GENERAL ASHCROFT

IMPORTANCE

THE FACT THAT HE CANNOT BE HERE THIS MORNING, BUT THE

THAT I

JUSTICE GIVES TO THIS INITIATIVE IS REFLECTED BY THE FACT

TWO OF

AM HERE, ALBEIT, A LITTLE BIT LATE, BUT ALSO AM JOINED BY

LORETTA

OUR MOST SENIOR LAWYERS IN THE CIVIL RIGHTS DIVISION,

AND

KING AND JOHN WODATCH, DEPUTY ASSISTANT ATTORNEY GENERAL,

ALSO OUR CHIEF OF THE DISABILITY RIGHTS SECTION IN THE CIVIL
RIGHTS DIVISION OF THE DEPARTMENT OF JUSTICE.

THE

SO WE ARE DELIGHTED TO BE HERE TO LISTEN TO THE ISSUES AND

ADVOCACY

CONCERNS THAT ARE RAISED BY CONSUMERS AND PROVIDERS AND

GROUPS AND WE COULDN'T BE HAPPIER TO BE HERE.

WE THINK THIS IS INCREDIBLY IMPORTANT AND WE ARE HERE AND
PREPARED TO LISTEN WELL.

SO THANK YOU VERY MUCH.

>> THANK YOU, MR. BOYD.

MS. KNISLEY?

>> THANK YOU, MEMBERS OF THE -- DISTINGUISHED MEMBERS OF THE
DIAS AND YOUR STAFF TODAY.

I AM HERE TO PROVIDE TESTIMONY REPRESENTING THE NATIONAL
ASSOCIATION OF THE STATE MENTAL HEALTH PROGRAM DIRECTORS.

I AM ALSO THE DIRECTOR OF MENTAL HEALTH FOR THE DISTRICT OF

BEEN

COLUMBIA, THE FIRST DIRECTOR OF MENTAL HEALTH FOR THE NEW DEPARTMENT OF MENTAL HEALTH HERE IN THE DISTRICT AND HAVE

DIRECTOR OF MENTAL HEALTH FROM THE STATE OF OHIO.

AND PRIOR TO MR. CURIE AND THE COMMONWEALTH OF PENNSYLVANIA.

I WOULD LIKE TO ADD MY APPLAUSE TO THE INITIATIVE AND IN PARTICULAR THE CREATION OF A NATIONAL COMMISSION ON MENTAL HEALTH.

AND I WOULD CONCUR WITH OUR EARLIER SPEAKER WITH RESPECT TO PARTICIPATION BY FAMILIES AND CONSUMERS ON THAT COMMISSION.

HAVE

I HAVE WORKED IN PUBLIC MENTAL HEALTH FOR OVER 30 YEARS AND

FIRST-HAND KNOWLEDGE OF THE BARRIERS WE FACE IN FEDERAL REGULATION ON POLICIES AND PROGRAMS.

ENDING

THESE BARRIERS AND THE CONTINUALLY AND SEEMINGLY NEVER

ILLNESS

STIGMA THAT PERSONS WITH MENTAL ILLNESS FACE CONTINUES TO EXACERBATE ALL OF THE PROBLEMS THAT PERSONS WITH MENTAL

AND REPRESENTATIVES OF ORGANIZATIONS FOR PERSONS WITH MENTAL ILLNESS WILL EXPRESS TO YOU HERE TODAY.

OVERCOME

IT'S ALWAYS A WONDROUS SUCCESS STORY WHEN SOMEONE CAN

THESE BARRIERS.

IT'S TRULY A SUCCESS STORY.

MORE OFTEN THAN NOT, THESE BARRIERS MAKE IT DIFFICULT FOR PERSONS WITH MENTAL ILLNESS TO LIVE OUT OF POVERTY AND TO RECEIVE THE TYPES OF REHABILITATION SERVICES, TREATMENT, AND HOUSING SUPPORTS THEY NEED.

AUGUST

NASHBIT PROVIDED WRITTEN COMMENTS TO THE INITIATIVE ON

27TH.

A I STRONGLY SUPPORT THESE COMMENTS AND WOULD LIKE TO ADD JUST
FEW ADDITIONAL THINGS TO SAY HERE THIS MORNING.
I WOULD LIKE TO BRING TO YOUR ATTENTION, AND IN THOSE
WRITTEN COMMENTS WE TALK AT LENGTH REGARDING THE ISSUE OF
INSTITUTIONS FOR MENTAL DISEASE.
THESE ARE CALLED IMD'S AND STATE PSYCHIATRIC HOSPITALS FALL
INTO THIS CATEGORY, WHICH MEANS THAT FOR ALL PERSONS BETWEEN THE
AGES OF 22 AND 64 WERE UNABLE TO GET MEDICAID REIMBURSEMENT FOR
PERSONS WHILE THEY'RE AT THE HOSPITAL.
WE ARE NOT HERE TO ASK YOU TO RESCIND THAT DESIGNATION.
HOWEVER, I WOULD LIKE TO POINT OUT THAT WHAT HAS HAPPENED
OVER THE COURSE OF TIME DATING BACK TO THE 1960S IS THAT WITHOUT
MEDICAID REIMBURSEMENT FOR THESE SERVICES, THAT HAS PUT US
GENERAL FURTHER BEHIND WITH RESPECT TO MEDICAID REIMBURSEMENT IN
FEDERAL AND HAS MADE IT VERY, VERY DIFFICULT FOR US TO USE THE
DIDN'T WAIVER PROGRAMS BECAUSE WE CAN'T CAP OUT OF SOMETHING WE
HAVE.
AND SO I URGE YOU TO LOOK AT SOME CREATIVE SOLUTIONS TO THAT
C PROBLEM THAT WOULD ALLOW US TO USE THE VERY INNOVATIVE 1915-
WAIVERS AND IT WOULD ALSO HELP US WITH 1950 WAIVERS AS WELL.

DOES FOR MANY OF YOU ON THE DIAS, THAT WON'T MEAN A LOT, BUT IT
OF MEAN SOMETHING TO OUR FRIENDS IN SAMHSA AND THE DEPARTMENT
HHS.

MEDICAID I WOULD ALSO LIKE TO MENTION ONE OTHER THING REGARDING
AND MEDICARE.

STATES, I HAVE JUST DONE A REVIEW PERSONALLY MYSELF OF OVER 20

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STATE MEDICAID PLANS WITH RESPECT TO MENTAL HEALTH SERVICES.
THAT NO TWO PLANS ARE THE SAME AND WE FIND OVER AND OVER AGAIN

SERVICE. WHAT YOU MIGHT FIND IN ONE REGION OF THE COUNTRY BEING MADE
AVAILABLE AS A STATE PLAN AMENDMENT, YOU WILL NOT FIND IN
ANOTHER REGION BECAUSE REGIONAL OFFICES MAKE DIFFERENT
DISTINCTIONS AND DESIGNATIONS OF WHAT'S AN ALLOWABLE

THAT'S A BARRIER THAT WE THINK COULD BE OVERCOME.

OUT. THIS AFTERNOON, YOU WILL HEAR TESTIMONY REGARDING PRICED

IT IS A VERY IMPORTANT STUDY OF WHAT HAS HAPPENED TO PERSONS
WITH DISABILITIES WHO NEED AFFORDABLE HOUSING.

>> MS. KNISLEY, MAY I ASK YOU TO WRAP UP, PLEASE?

>> OKAY.

>> THANKS.

>> ONE MORE COMMENT AND I WILL COMPLETE THIS.

MENTAL IN THE DISTRICT OF COLUMBIA TODAY, A PERSON ON -- WITH A

TO DISABILITY IS REQUIRED TO SPEND 90% OF THAT DISABILITY, SSI,

SOME LIVE IN AN AFFORDABLE HOUSING PLACE WITHOUT A VOUCHER OF
TYPE OR A RENTAL SUBSIDY.
THOSE SUBSIDIES SIMPLY ARE NOT AVAILABLE.
WE NEED FIVE TIMES MORE THAN WE HAVE TODAY, JUST TO MEET OUR
CURRENT NEED.

AFTERNOON SO I ASK YOU TO LISTEN CAREFULLY TO THE TESTIMONY THIS
FROM REPRESENTATIVES SPEAKING SPECIFICALLY ON THIS ISSUE.
THANK YOU VERY MUCH.

>> THANK YOU, MS. KNISLEY.

MR. SMITH?

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>> GOOD MORNING.
IT IS A PLEASURE TO BE HERE AND I THANK EVERYONE FOR COMING
OUT.

ADDICTIONS I'M FROM BLOOMINGTON, INDIANA, AND I REPRESENT THE
TREATMENT FACILITIES.

THAT I HAVE A LIST OF THINGS HERE THAT -- SOME OF THE BARRIERS

WE FACE IN THE ADDICTIONS FIELD.
ONE IS IT'S UP TO SIX WEEKS WAITING PERIOD FOR AN ADDICTION
ASSESSMENT IN PARTS OF INDIANA.

SOME AGENCIES HAVING 40 OR MORE PEOPLE IN AN INTENSIVE
OUTPATIENT PROGRAM, WHICH IS ABBREVIATED, IOP, INTENSIVE
OUTPATIENT, THREE MAJOR LOSS OF ADDICTION RESIDENTIAL AND
DETOX

BEDS IN INDIANA IN THE LAST FIVE YEARS, ABOUT ONE HALF OF
BEDS

ARE GONE.

CLOSING AND DOWNSIZING CHRONIC ADDICTION BEDS IN THE STATE
OPERATED HOSPITALS.

INDIANA SINGLE STATE AGENCY, THE DIVISION OF MENTAL HEALTH
AND

ADDICTIONS HAS A POLICY THAT STATES, THEY ARE NOT
RESPONSIBLE

FOR HOUSING ANY ADDICTED PERSONS, THUS DETOX AND
RESIDENTIALS

BECOME THE RESPONSIBILITY OF JAILS, PRISONS, MISSIONS, AND
MOSTLY GRASS ROOT RECOVERY HOUSES.

GRANTS THAT MAY BE ABLE TO ASSIST INDIANA ARE NOT PUBLICIZED
ENOUGH OR IN TIME TO PREPARE A GRANT APPLICATION.

STUDIES BY THE DIVISION OF MENTAL HEALTH AND ADDICTIONS
INDICATE

ABOUT 682,000 INDIANA CITIZENS NEED ADDICTION TREATMENT.

ONLY 41,000 SAW TREATMENT IN THE STATE LAST YEAR.

THOSE SAME REPORTS IDENTIFY ONLY 60,000 WOMEN NEEDING
TREATMENT

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AND ONLY 3,600 RECEIVING TREATMENT.

INDIANA ONLY ALLOWS COMMUNITY HEALTH CENTERS TO ASSESS
MEDICAID

REHAB, OPTIONAL DOLLARS THAT COULD BE USED TO ENHANCE
SERVICES

AND OTHER PROVIDER PROGRAMS.

THIS LIMIT GIVES THE MENTAL HEALTH CENTERS A MAJOR
COMPETITIVE

ADVANTAGE OVER MORE TRADITIONAL ADDICTIONS PROVIDERS.

ME BEING A RECOVERING PERSON MYSELF, I HAD MY STRUGGLES.

I LIVED IN THE STREETS AND I AM A RECOVERING PERSON AND I
THANK

GOD FOR MY LIFE TODAY.

BACK

HE HAS GIVEN ME A LIFE OF RECOVERY TODAY WHERE I CAN REACH

THAT

FOR MY FELLOW MAN AND MY FELLOW SISTER AND GIVE A HAND AND

IS MY RESPONSIBILITY TODAY.

AND I JUST AGAIN THANK ALL OF YOU FOR COMING OUT.

THANKS.

>> THANK YOU VERY MUCH.

PLEASE, SIR?

>> GOOD MORNING.

I WANT TO SAY GOOD MORNING TO THE PANEL AND THE PEOPLE IN

ATTENDANCE IN THE AUDIENCE TODAY.

I JUST WANT TO WISH YOU PEACE AND BLESSINGS.

MY NAME IS BOBBY COWARD.

MEMBER

I AM A CHAIRPERSON, A SPOKESMAN FOR CAPITAL AREA DAP, A

OF THE D.C. COUNCIL FOR INDEPENDENT LIVING AS WELL AS AN AIR

FORCE VETERAN.

NATIONAL

I'M HERE SPEAKING ON BEHALF OF NATIONAL ADAP TODAY, A

NETWORKS

GRASS ROOTS DISABILITY RIGHTS ORGANIZATION WITH LOCAL

45

THROUGHOUT THE COUNTRY.

INSTITUTIONAL

ADAP IS ADVOCATING FOR A REFORM WITH 35-YEAR-OLD

BIAS AND LONG-TERM CARE SYSTEM IN THE UNITED STATES TODAY.

SIMPLY STATED, OUR LONG-TERM CARE SYSTEM IS BROKEN, IT'S IN

CRISIS.

PEOPLE WITH DISABILITY, REGARDLESS OF AGE AND THEIR FAMILIES
WANT SUPPORT AND SERVICES IN THE COMMUNITY.
BUT THE FUNDING AND REGULATORY SERVICES IN THE COMMUNITY ARE
FOCUSED ON NURSING HOMES AND OTHER INSTITUTIONS.
WE DON'T NEED STUDIES.
YOU KNOW, YOU DON'T NEED TO DO A STUDY OF A STUDY THAT
ALREADY
BEEN STUDIED.
WE NEED ACTION FROM EXECUTIVE AND LEGISLATIVE BRANCHES TO
REFORM
THE SYSTEM.
ADAP HAS SUBMITTED DETAILED RECOMMENDATIONS ON THE EXECUTIVE
ORDER, BUT TODAY I WANT TO SUMMARIZE WHAT WE BELIEVE WILL
MOVE
US TO A COMMUNITY FIRST, LONG-TERM CARE POLICY IN THIS
COUNTRY.
FIRST, THE TEST OF THE OLMSTEAD DECISION WILL BE HOW MANY
PEOPLE
WE CAN GET OUT OF NURSING HOMES AND OTHER INSTITUTIONS.
SECOND, HOW MANY PEOPLE ARE KEPT OUT OF NURSING HOMES AND
OTHER
INSTITUTIONS.
GIVE ME A MOMENT.
THE OLMSTEAD CASE WAS NOT ABOUT PLANS, BUT ABOUT REAL
CHOICE,
GETTING AND STAYING OUT OF NURSING HOMES AND OTHER
INSTITUTIONS.
HERE TODAY WE MEET WITH ME OUR FOLKS WHO ARE AND HAVE BEEN
IN
NURSING HOMES.

THEY CAN SPEAK ON THE INDENTATIONS THAT OUR LONG-TERM CARE POLICIES HAVE FORCED ON THEM.

BASIS ADAP RECOMMENDS THAT EACH STATE MUST REPORT ON A QUARTERLY

GOT TO HHS AND CMS HOW MANY PEOPLE THEY HAVE GOTTEN OUT OF --

HOMES OUT AND HOW MANY PEOPLE THEY HAVE DIVERTED FROM NURSING

AND OTHER INSTITUTIONS.

NEED THERE NEEDS TO BE AN ONGOING PROCESS TO IMPLEMENT THE RECOMMENDATION THAT COME FROM HHS, PEOPLE WITH DISABILITIES

RECOMMENDATIONS. TO GET AT THE TABLE TO IMPLEMENT SUBSTANTIAL

CONTINUE WE NEED -- WE WILL NOT TOLERATE RECOMMENDATIONS THAT

THE SYSTEM AS IT IS TODAY.

HHS STATES NEED THE FLEXIBILITY AND THE FUNDING TO IMPLEMENT THE OLMSTEAD DECISION, BUT THEY ALSO MUST BE HELD ACCOUNTABLE BY

OFFICE OF CIVIL RIGHTS.

TO HHS AND THE OFFICE OF CIVIL RIGHTS MUST BE GIVEN THE POWER

MOST WITHHOLD FEDERAL FUNDING IF STATES DO NOT COMPLY WITH THE

INTEGRATIVE SETTING.

ONE FOR EXAMPLE, THE STATE OF CALIFORNIA AND THE CITY OF SAN FRANCISCO ARE PLANNING TO BUILD A NURSING FACILITY OF OVER

THOUSAND BEDS, WHICH IS LAGUNA HUNDA.

THIS IS IMMORAL AND ILLEGAL, OUTRAGE.

STATE HHS AND OCR MUST INVOKE THE OLMSTEAD DECISION AND CLEARLY

THAT THIS IS A VIOLATION OF THE MOST INTEGRATIVE SETTING,

MANDATE AND WITHHOLD FEDERAL FUNDING.

>> MR. COWARD, IF YOU COULD SUMMARIZE, PLEASE.

>> ALL RIGHT.

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THAT WAS TAKING UP MOST OF TIME.

>> THANKS.

ADDRESSED >> THESE ISSUES ARE THE MOST -- THESE ISSUES MUST BE

FOR THE COMMUNITY FIRST POLICY TO WORK EFFECTIVELY.

REGULATIONS REMOVE THE UNNECESSARY MEDICAID, HEALTH RULES, AND

ON PROGRAMS THAT ARE ESSENTIAL SUPPORT SERVICES.

MAKE A NATIONAL EFFORT TO RECRUIT AND PAY A LIVABLE WAGE

BENEFITS TO PERSONAL ASSISTANCE.

ATTENDANCE, I'M SORRY.

THERE IS A MASSIVE SHORTAGE OF HANDS-ON WORKERS TO PROVIDE
SERVICES AND SUPPORTS.

AND FOCUS ON ADDRESSING THE SHORTAGE OF ACCESSABLE, AFFORDABLE
INTEGRATIVE HOUSING FOR FOLKS COMING OUT OF NURSING HOMES

OTHER INSTITUTIONS AND THOSE AT IMMINENT RISK OF GOING IN.

FUNDS MUST BE SPECIALLY ALLOCATED FOR THIS PURPOSE.

AND HUD PROGRAMS MUST BE REVIEWED FOR THEIR INSTITUTIONAL BIAS

REFORMED TO PRIORITIZE ACCESSIBLE, AFFORDABLE, INTEGRATED
HOUSING PROGRAMS AND POLICIES.

FOR FINALLY, I WOULD BE REMISS NOT TO PUT ON THE RECORD THE NEED

THE BUSH ADMINISTRATION TO SUPPORT SENATE BILL 19 -- I MEAN,

INTRODUCED

1298, THIS IS THE MICASA BILL THAT HAS BEEN RECENTLY
BY SENATOR HAWKINS.

TO

THE PASSAGE OF THIS BILL WILL BE A MASSIVE STEP ON THE ROAD
REFORM THE TOTAL LONG-TERM CARE SYSTEM BY GIVING PEOPLE REAL
CHOICE AND WHERE AND HOW THEY RECEIVE THEIR SUPPORTS.
THANK YOU.

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>> THANK YOU VERY MUCH.
PLEASE.

>> GOOD DAY, LADIES AND GENTLEMEN.

THE

MY NAME IS MARY KISSEE, AND MY SON TOBY JONES IS SITTING IN
BACK.

HE CHOOSE NOT TO COME UP.

BIOLOGICALLY, I AM TOBY'S GRANDMOTHER.

THROUGHOUT

TOBY'S BIOLOGICAL MOTHER DRANK AND TOOK DRUGS, LSD,
HER PREGNANCY.

TOBY NOW HAS SEVERE NEUROLOGICAL PROBLMES.

FINDING THE CORRECT DIAGNOSIS FOR TOBY WAS A NIGHTMARE,
MISDIAGNOSIS LED TO A WRONG MEDICATION PLAN.

TIME HE

HE WAS PRESCRIBED STIMULANTS WHEN HE WAS FOUR AND BY THE
WAS 10, HE HAD DEVELOPED A PERMANENT HEART CONDITION.

NIGHT

THE STIMULANTS DID HELP WITH TOBY'S BEHAVIOR, BUT NOT HIS
TERRORS, PSYCHOTIC SYMPTOMS, OR OBSESSIVE COMPULSIVE
DISORDEREDS.

WHEN TOBY WAS FIVE, WE TRAVELED 300 MILES TO
SAN FRANCISCO FOR AN EVALUATION.
THEY COULDN'T FIND A DIAGNOSIS.
THE LOCAL NEUROLOGIST TOLD ME THAT WE DON'T TREAT CHILDREN
LIKE
TOBY AND POLITELY ASKED ME TO LEAVE HIS OFFICE.
TOBY WAS TURNED DOWN BY MENTAL HEALTH, WHICH SAID THAT
TOBY'S
PROBLEM WAS ORGANIC AND NOT A MENTAL HEALTH PROBLEM.
IT TOOK YEARS TO LOCATE A PSYCHIATRIST TO WORK WITH TOBY'S
PROBLEMS AND I HAD TO TRAVEL 130 MILES EACH WAY.

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BECAUSE OF BUDGET CUTS, IMPORTANT DIAGNOSTIC TOOLS ARE NO
LONGER
AVAILABLE TO CHILDREN WITH MEDICAL.
THESE ARE SOME OF THE OBSTACLES MY HUSBAND AND I HAVE FACED
WITH
PROVIDING GOOD CARE WITH TOBY.
BECAUSE OF PROBLEM BEHAVIOR, MY HUSBAND AND I PURCHASED A
HOME
IN A REMOTE, RURAL AREA.
ALTHOUGH THE LAST POLE FOR ELECTRICITY IS ONLY A MILE AWAY,
THEY
WANT \$32,000 TO PROVIDE ELECTRICITY TO OUR HOME.
WITHOUT ELECTRICITY, TOBY CANNOT BENEFIT FROM EDUCATIONAL
TELEVISION OR COMPUTERS.
IT TOOK OVER TWO YEARS TO FIND A PERSON TO PROVIDE RESPITE
CARE
IN OUR HOME WITH NO ELECTRICITY.
I HAVE NO HEALTH INSURANCE OR RETIREMENT BECAUSE I CANNOT
WORK

AND CARE FOR TOBY AT THE SAME TIME.

HE REQUIRES AROUND-THE-CLOCK SUPERVISION.

I TRAVEL 90 MILES EACH WAY FOR SPECIALIZED COUNSELING.

I DRIVE TOBY TO SCHOOL EACH MORNING BECAUSE THE SCHOOL
CANNOT

PROVIDE AN A.M. AID TO RIDE WITH TOBY AND HE REQUIRES
SUPERVISION ON THE BUS.

TOBY NEEDS FRIENDS, BUT ALL OF HIS ACTIVITIES HAS TO BE
SUPERVISED.

THESE ARE JUST THE HIGHLIGHTS.

I BELIEVE THAT AS A RELATIVE WHO HAS GIVEN UP MY
INDEPENDENCE

INCLUDING EMPLOYMENT TO STAY HOME AND CARE FOR A DISABLED
CHILD,

I SHOULD BE GIVEN THE SUPPORT THAT INCLUDES MEDICAL
INSURANCE

AND ELECTRICITY.

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IN CLOSING, I WANT TO SAY AS TOBY'S CARETAKER, MY HUSBAND
AND I

HAVE ACCEPTED THE RESPONSIBILITY TO PROTECT TOBY FROM HIS
SELF-DESTRUCTIVE BEHAVIORS AND FROM THE POTENTIAL BEHAVIORS
THAT

HE HAS EVERY DAY.

I ALSO BELIEVE THAT IT IS THE COMMUNITY'S RESPONSIBILITY TO
PARTICIPATE IN THE CARE OF ALL CHILDREN WHO SUFFER FROM
THESE

MENTAL HEALTH DISABILITIES.

I REMIND YOU THAT IT IS NOT THE CHILDREN THAT TAKE THE DRUGS
AND

DO THE ALCOHOL.

THANK YOU VERY MUCH.

THANK YOU VERY MUCH, THE FOUR OF YOU.

FOUR

MS. FOWLER, BEFORE WE MOVE TO YOU, I WOULD LIKE THE NEXT

INDIVIDUALS PROVIDING TESTIMONY TO PLEASE COME AND TAKE THE SEATS.

WE'VE ALSO HAD TWO PEOPLE JOIN US AT THE DIAS.

YOU'RE

AND JUST IN TERMS OF GOOD MANNERS, SO YOU KNOW TO WHOM

INTRODUCE

SPEAKING, I WOULD LIKE TO GIVE THEM AN OPPORTUNITY TO

THEMSELVES PLEASE.

>> MY NAME IS PAUL CONWAY.

MANAGEMENT

I SERVE AS CHIEF OF STAFF AT THE OFFICE OF PERSONNEL

FOR KAY JAMES.

AND I'M HERE REPRESENTING KAY TODAY FOR THE NEW FREEDOM

INITIATIVE.

>> YES.

MY NAME IS GARY REED.

DISABILITY

I'M THE ACTING ASSISTANT SECRETARY FOR THE OFFICE OF

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EMPLOYMENT POLICY IN THE LABOR DEPARTMENT.

AND I'M DELIGHTED TO BE HERE.

THANK YOU.

>> THANK YOU VERY MUCH.

MS. FOWLER, WE TURN TO YOU, PLEASE.

>> GOOD MORNING.

MY NAME IS LADONNA FOWLER.

I'M A CHIPPEWA.

I LIVE ON THE FLIGHT HEAD RESERVATION IN MONTANA.

I REPRESENT THE AMERICAN INDIAN REHABILITATION RIGHTS ORGANIZATION OF WARRIORS.

TO I'VE COME TO TALK TO YOU TODAY ABOUT -- ACTUALLY, I'VE COME BRING THE VOICE TODAY OF PEOPLE WITH DISABILITIES IN INDIAN COUNTRY.

SAID, AFTER TALKING TO ELDERS AND PEOPLE WITH DISABILITIES, THEY

AND THESE ARE THEIR WORDS:

TO PAINT YOU A PICTURE OF HOW WE DO WITHOUT ADEQUATE AND APPROPRIATE HEALTH CARE SERVICES, ESPECIALLY WHEN WE RECEIVE ONE THIRD THE HEALTH CARE SERVICES THAT A MEDICAID BENEFICIARY RECEIVES.

I'VE COME TO TELL YOU ABOUT EMPHASES ON EMPLOYMENT.

COUNTRY YET, HOW CAN YOU TALK TO US ABOUT EMPLOYMENT IN INDIAN

HAVE WHEN WE CAN'T GET OUT OF BED IN THE MORNING, WHEN WE DON'T

AND ACCESSIBLE HOUSING, WE DON'T HAVE ACCESSIBLE TRANSPORTATION,

TIME. WE DON'T HAVE WAYS TO GET THOSE WITHIN OUR SYSTEM AT THIS

DISABILITY THEY SAID TO TELL YOU THAT WE DON'T HAVE ACCESS TO

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SERVICES BECAUSE WE'RE RURAL AND REMOTE.

WITH AND A LOT OF TIMES SERVICE PROVIDERS DO NOT KNOW HOW TO WORK

FAR US AND USE EXCUSES ABOUT OUR LANGUAGE, OUR CULTURE, AND HOW
AND REMOTE WE ARE.
TELL THEY SAID TO TELL YOU THAT IN INDIAN COUNTRY IT'S HARD TO
YOU ABOUT ALL THE NEEDS THAT ARE THERE BECAUSE THERE ARE SO
MANY.
NEED AGAIN, I RELATE BACK TO NO ADEQUATE HEALTH CARE, THAT WE
MORE DOLLARS INTO OUR HEALTH CARE SYSTEM.
BECAUSE WHEN WE HAVE ADEQUATE HEALTH CARE, WE'LL BE ABLE TO
BE HEALTHY AND MORE WELL.
WE DON'T HAVE ACCESSIBLE HOUSING.
THERE'S A SHORTAGE IN INDIAN COUNTRY NOW WITH HOUSING.
SO WE BECOME AT THE BOTTOM OF THE LIST IN PRIORITIZING FOR
HOUSING AND ACCESSIBLE HOUSING.
ON TRIBES NEED ACCESS TO TECHNICAL ASSISTANCE AND INFORMATION
HOW TO MAKE HOMES ACCESSIBLE AND HOW TO UTILIZE CONCEPTS OF
UNIVERSAL DESIGN AND VISIBILITY.
DISABILITIES WE NEED TRANSPORTATION JUST LIKE OTHER PEOPLE WITH
NEED TRANSPORTATION IN OUR SYSTEMS.
ACQUIRE AND WE NEED YOU TO WORK WITH OUR TRIBAL GOVERNMENTS TO
THIS.
IN A LOT OF INSTANCES WE ALSO HAVE NO RUNNING WATER AND
ELECTRICITY IN OUR COMMUNITIES.
ALL AND HOW CAN WE BECOME PART OF THE ASSISTIVE TECHNOLOGY AND
WELL. THE TECHNOLOGY OUT THERE WITHOUT THESE THINGS IN PLACE AS

AS I SAID, THERE'S A LOT OF NEEDS IN INDIAN COUNTRY. AND I
THINK THE CRITICAL THING IS THAT WE NEED EQUAL ACCESS AND
EQUAL
OPPORTUNITY FOR ALL OF YOU THAT ARE HERE TODAY, THAT YOU
INCLUDE
TRIBAL GOVERNMENTS WHEN YOU TALK ABOUT WHATEVER YOU'RE DOING
IN
THE NEW FREEDOM INITIATIVE.
WE NEED TO YOU TO THINK ABOUT HOW YOU WILL GIVE TRIBES THE
THE
OPPORTUNITY TO ACCESS THE DOLLARS THAT THE STATES WILL HAVE
BENEFIT OF IMPLEMENTING THESE NEW INITIATIVES.
PEOPLE
WE NEED YOU TO HEAR OUR VOICES IN THE INDIAN COUNTRIES,
WITH DISABILITIES, BECAUSE WE'RE MOST TIMES NOT ON THE RADAR
BUT
SCREEN FOR ANY POPULATION, LET ALONE, NOT JUST OUR TRIBES,
FOR THE NATIONAL VIEW AS WELL.
I HAD A LOT OF THINGS, AND I THINK THE BOTTOM THING THAT I
INDIAN
REALLY WANTED TO SAY IS THAT THERE ARE SO MANY NEEDS IN
SOLVE
COUNTRY FOR PEOPLE WITH DISABILITIES, AND WE NEED WAYS TO
THESE.
WE NEED YOU TO HELP US.
AND WE NEED OUR TRIBES TO BE ABLE TO ACCESS THE SAME THINGS
THAT
OTHER STATES ARE ACCESSING.
AND MY FINAL STATEMENT IS THAT WE NEED AN OPPORTUNITY TO
TALK.
AND WE NEED A NATIONAL SUMMIT ON DISABILITY FOR INDIAN
COUNTRY,

WHERE WE WOULD INCLUDE TRIBAL LEADERS, NATIVE PEOPLE WITH
STRATEGIES
DISABILITIES, AND ALL OF YOU, TO HELP US FIGURE OUT

TO INCLUDE US IN THESE NEW FREEDOM INITIATIVES.

THANK YOU.

>> THANK YOU, MS. FOWLER.

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MS. O'HARA, BEFORE I GO TO YOU, LET ME JUST ASK,
GREEN
THOSE OF YOU WHO ARE PROVIDING TESTIMONY THAT ARE HOLDING

ASSEMBLE
CARDS, IF YOU HAVE NOT ALREADY DONE SO, IF YOU WOULD,

IN THE LAST ROW PLEASE.

THANK YOU.

MS. O'HARA.

>> GOOD MORNING.

MY NAME IS AILEEN O'HARA.

IS A
I'M REPRESENTING STAND TOGETHER OF MONTGOMERY COUNTY, WHICH

COUNTY.
SELF ADVOCACY GROUP SUPPORTED BY THE ARC OF MONTGOMERY

I WAS BORN WITH CEREBRAL PALSY AND HAVE BEEN LUCKY ALL OF MY
LIFE TO HAVE HAD SOME OF THE OPPORTUNITIES THAT I HAVE HAD.

ASKED
BUT I HAVE TALKED TO SEVERAL MEMBERS OF OUR GROUP WHO HAVE

ME TO BRING MY CONCERNS AS WELL AS THEIR CONCERNS.

IS
ONE OF THE CONCERNS WE HAVE IN MONTGOMERY COUNTY IS THAT IT

ENOUGH
CURRENTLY VERY, AT THE MOMENT, CURRENTLY VERY HARD TO GET
AFFORDABLE HOUSING BECAUSE THERE JUST DOESN'T SEEM TO BE

PROGRAMS THAT ARE ADDRESSING THE HOUSING ISSUE.
ONE OF THE PROGRAMS THAT I'M CURRENTLY INVOLVED IN IS A HOME
OF
YOUR OWN PROGRAM.
AND THIS IS THE FIRST PROGRAM THAT I HAVE SEEN IN MONTGOMERY
COUNTY THAT GIVES PEOPLE WITH DISABILITIES ANY CHANCE OF
MOVING
OUT OF THEIR PARENT'S HOME, OUT OF GROUP HOMES, WHATEVER
THEIR
SITUATION IS, AND INTO SOMETHING OF THEIR OWN.
AND THIS PROGRAM IS A STEP BY STEP PROGRAM THAT HELPS THEM.
BUT WE NEED MORE EXPOSURE FROM THE FEDERAL GOVERNMENT ABOUT
THIS

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PROGRAM.
AND WE NEED HUD TO STEP IN WHEN THE JOSEPH KENNEDY
FOUNDATION
GRANT ENDS.
WE NEED HUD TO STEP IN AND KEEP THIS PROGRAM GOING BECAUSE
THIS
IS, BY FAR, THE ONLY WAY THAT PEOPLE IN MONTGOMERY COUNTY
WITH
DISABILITIES ARE GOING TO GET OUT ON THEIR OWN, IS WITH HELP
FROM STATE, LOCAL, AND NATIONAL LEADERS.
MY SECOND THING IS THAT THERE ARE MANY BARRIERS IN FEDERAL
EMPLOYMENT FOR PEOPLE WITH DISABILITIES, EVEN THOUGH WE'VE
COME
THE DISTANCE THAT WE HAVE.
THERE'S STILL A LOT OF WORK.
I MYSELF HAVE BEEN EMPLOYED BY THE FEDERAL GOVERNMENT FOR
TEN

THE YEARS AND HAVE BEEN A GS-4 FOR THOSE TEN YEARS AND NOT GIVEN
CHANCE TO MOVE UP, BECAUSE WHEN I ASK FOR TRAINING I'M TOLD,
IT'S NOT GOING TO BE PART OF YOUR DUTIES SO FORGET ABOUT IT.
I'M TOLD VARIOUS EXCUSES OF WHY I CAN'T HAVE THE TRAINING
THAT I WOULD LIKE TO HAVE.
FROM A I HAVE A DEGREE IN WORD PROCESSING AND OFFICE MANAGEMENT
TWO-YEAR COLLEGE.
AND LIKE I SAY TO PEOPLE, YOU KNOW, LOOK, I'M SORRY, BUT THE
TIME FOR EXCUSES IS OVER.
ON I WOULD LIKE TO SEE ALL OF YOU LOOK AT YOUR FEDERAL POLICIES
AHEAD. EMPLOYMENT FOR PEOPLE WITH DISABILITIES AND LET'S MOVE
FINALLY, ONE OF THE OTHER THINGS THAT IS A BIG CONCERN IN
MONTGOMERY COUNTY IS TRANSPORTATION FOR PEOPLE WITH
DISABILITIES.

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CURRENTLY, YES, WE DO HAVE METRO ACCESS.
BUT HALF THE TIME IT DOESN'T WORK.
TO PEOPLE ARE LEFT STANDING FOR -- WAITING FOR HOURS TO RIDES
WORK, COMMUNITY ACTIVITIES.
IT'S AND FOR PERSONS LIKE ME WHO CAN USE A REGULAR SYSTEM, YES,
GOOD THAT WE CAN USE IT.
BUT WHAT ABOUT EVENING HOURS WHEN IT MIGHT NOT BE SAFE FOR
AT PEOPLE WITH DISABILITIES TO BE WAITING AT BUS STOPS, WAITING

METRO STATIONS.

WE NEED HELP IN THAT AREA TOO.

SO I WOULD SAY THAT ALTHOUGH WE'VE COME A LONG WAY, THERE'S STILL A LOT TO BE DONE.

THANK YOU VERY MUCH.

>> THANK YOU, MS. O'HARA.

MR. OTTO?

>> THANK YOU.

GOOD MORNING, EVERYONE.

MY NAME IS DALE OTTO.

I'M PRESIDENT AND CEO OF THE COLUMBIA LIGHTHOUSE FOR THE BLIND.

OUR HEADQUARTERS IS IN WASHINGTON, D.C., BUT THE ORGANIZATION

HAS BEEN INVOLVED IN TRAINING FOR INDIVIDUALS FOR EMPLOYMENT AND

IN ASSISTIVE TECHNOLOGY ON A NATIONWIDE BASIS.

I APPRECIATE THE OPPORTUNITY TO BE HERE TODAY AND TO SPEAK TO

YOU ABOUT SOME OF OUR CONCERNS AND ISSUES REGARDING THE NEW FREEDOM INITIATIVE AND PROGRAMS THAT WE ENCOURAGE YOU, AS

REPRESENTATIVES OF FEDERAL AGENCIES AND THE BUSH ADMINISTRATION

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TO LOOK AT IN THE TIME AHEAD.

FIRST OF ALL, AT A TIME WHEN OUR ECONOMY HAS BEEN GROWING OVER

THE PAST DECADE, WE STILL FIND THE UNEMPLOYMENT RATE FOR BLIND

AND VISUALLY IMPAIRED WORKING AGED ADULTS TO BE AROUND 70%.

OUR

AFTER WE GET PAST THE POINT OF LAMENTING THAT AND RINGING

HANDS ABOUT IT, WHAT CAN BE DONE?

DISABILITIES
NUMBER ONE, IT'S ESSENTIAL THAT INDIVIDUALS WITH

RECEIVE OPPORTUNITIES FOR TRAINING AND ACCESS TO TECHNOLOGY.

THERE IS NO FUTURE IN EMPLOYMENT UNLESS INDIVIDUALS HAVE THE

TECHNOLOGY AND COMPUTER SKILLS TO COMPETE SUCCESSFULLY AND

EFFECTIVELY IN THE JOB MARKET.

SECONDLY, INDIVIDUALS MUST HAVE THE OPPORTUNITY TO COMPETE.

WE BELIEVE THAT COMPETITION IS A WORD THAT SOMETIMES IS

DISMISSED.

THERE

THE STANDARDS AND THE BAR MUST BE RAISED ON ALL SIDES, AND

MUST BE INCENTIVES FOR EMPLOYERS TO HIRE INDIVIDUALS WITH

COMPETE

DISABILITIES, TO GIVE INDIVIDUALS THE OPPORTUNITIES TO

IN A GLOBAL ECONOMY.

MEANING

WE HAVE FOUND IN OUR EFFORTS THAT ASSISTIVE TECHNOLOGY,

ENHANCEMENT

COMPUTERS THAT UTILIZE, FOR EXAMPLE, SPEECH, PRINT

WAY

DEVICES, OR MAKE TECHNOLOGY ACCESSIBLE, IS TRULY THE ONLY

THAT INDIVIDUALS CAN NOT ONLY COMPETE IN EMPLOYMENT, BUT IN

SCHOOL AND AT HOME.

WE ARE AN INFORMATION TECHNOLOGY SOCIETY.

AND IT IS ESSENTIAL THAT INITIATIVES SUCH AS SECTION 508 BE

FULLY ENFORCED.

AS AN ORGANIZATION, WE DO NOT BELIEVE IN REGULATION FOR

REGULATION'S SAKE.

THE
BUT BY THE SAME TOKEN, WHEN A REGULATION CAN BE A BENEFIT TO
THERE
CITIZENS OF THIS COUNTRY AND THE ECONOMY OF THIS COUNTRY,
IS VALIDITY FOR IT.

AND SECTION 508 AND THE IMPACT IT WILL HAVE, NOT ONLY ON THE
ONE
FEDERAL GOVERNMENT, BUT ON THE FEDERAL CONTRACTORS, IS TRULY
OF THOSE.

ONE LAST POINT ON TECHNOLOGY.

WE WERE PRIVILEGED LAST SUMMER TO HAVE THE OPPORTUNITY TO
STUDENTS
PROVIDE TECHNOLOGY TRAINING FOR MIDDLE AND HIGH SCHOOL
IN THE GREATER WASHINGTON AREA.

WE PROVIDED INDIVIDUALS WITH OPPORTUNITIES, NOT ONLY TO
LEARN
ABOUT TECHNOLOGY, BUT TO BUILD THEIR OWN WEBPAGES.

IT WAS TRULY A WONDERFUL EXPERIENCE TO SEE THESE YOUNG
PEOPLE
TAKE PRIDE IN THE FACT THAT THEY ARE NOW COMPETITIVE AND
HAVE

THE SAME SKILLS, AND IN SOME CASES MORE SKILLS, THEN SOME OF
THEIR FELLOW STUDENTS.

WHEN YOU WALKED AROUND THE ROOM AND SAW THOSE STUDENTS
DEMONSTRATING THE WEBPAGES THAT THEY HAD DEVELOPED WITH THE
SUPPORT OF OUR STAFF AND TAKING PRIDE IN THE FACT THAT THEY
COULD TRULY RETURN TO SCHOOL THIS YEAR WITH GREATER
KNOWLEDGE

AND CONFIDENCE ABOUT THEIR ABILITIES TO DEAL WITH
TECHNOLOGY, IT

WAS A VERY, VERY MOVING EXPERIENCE.

TO BEYOND TECHNOLOGY, WHAT ARE SOME OF THE KEY THINGS THAT NEED
HAPPEN?

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NUMBER ONE, FOR BLIND INDIVIDUALS IN PARTICULAR, THE SOCIAL
SECURITY LINKAGE, WHICH WAS ELIMINATED IN 1995, NEEDS TO BE
RESTORED.
AND THERE'S CONGRESSIONAL LEGISLATION IN THE HOUSE SPONSORED
BY CONGRESSMAN BOB EHRLICH FROM MARYLAND THAT WOULD DO THAT.
BE THAT'S KEY BECAUSE WE CAN NOT ALLOW GOVERNMENT PROGRAMS TO
AND DISINCENTIVES AND PENALIZE INDIVIDUALS WHO WANT TO SUCCEED
TO DO COMPETE EFFECTIVELY IN OUR ECONOMY TO HAVE THE OPPORTUNITY
SO.
CONGRESSMAN ALSO IT'S ESSENTIAL THAT LEGISLATION SPONSORED BY
SERVICES MICHAEL CAPUANO OF MASSACHUSETTS TO ALLOW VISION REHAB
SUPPORTED TO BE COVERED UNDER MEDICARE BE PASSED BY CONGRESS AND
BY FEDERAL AGENCIES.
HIP IT IS IRONIC, ISN'T IT, THAT IF AN INDIVIDUAL BROKE THEIR
AND WAS LOSING THEIR VISION AND --
>> MR. OTTO, IF I MIGHT ASK YOU TO WRAP UP PLEASE?
>> OKAY. THANK YOU.
>> THANK YOU.
>> IN SUMMARY, INDEPENDENCE IS ONLY ACHIEVED WHEN ALL OF US
HAVE

OF

THE SUPPORT AND THE CONFIDENCE AND THE ABILITY TO BE A PART

OVERALL GENERAL SOCIETY.

AND I URGE THE ADMINISTRATION TO TAKE INITIATIVES THAT HAVE

LONG-TERM EFFECTS IN ENSURING THAT THAT CAN OCCUR.

>> THANK YOU, SIR.

>> MS. SULLIVAN?

>> THANK YOU.

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MY NAME IS KATHY SULLIVAN.

SERVICE

I'M A POLICY ANALYST, AND I'M HERE TODAY ON BEHALF OF

EMPLOYEES INTERNATIONAL UNION.

PROVIDING

SCIU REPRESENTS OVER 200,000 INDIVIDUALS NATIONWIDE,

DISABILITIES.

HOME AND COMMUNITY-BASED SERVICES TO PEOPLE WITH

AND A WELL QUALIFIED WORK FORCE IS AN INTEGRAL COMPONENT TO

PROVIDING HOME AND COMMUNITY-BASED SERVICES.

FAMILY

MANY OF OUR 1.4 MILLION MEMBERS NATIONWIDE ARE THEMSELVES

MEMBERS OR CONSUMERS OF SERVICES.

AND WE KNOW THAT THE POLICIES THAT ARE ESTABLISHED BY THIS

ON

ADMINISTRATION AND ITS FEDERAL AGENCIES HAVE A DIRECT IMPACT

OUR MEMBERSHIP AND THEIR FAMILIES.

SO WHAT I'M HERE TO TALK TO YOU TODAY ABOUT, THE CRITICAL

AND

IMPORTANCE OF RECRUITING AND RETAINING A WELL QUALIFIED HOME

COMMUNITY-BASED WORK FORCE.

WE HAVE SPECIFIC RECOMMENDATIONS.

TO THE DEPARTMENT OF LABOR WE WOULD ASK THAT -- WE REPRESENT
PEOPLE PROVIDING PERSONAL CARE SERVICES IN PEOPLE'S HOMES.
AND AS WE ALL KNOW, THAT HAS GROWN DRAMATICALLY OVER THE
YEARS.

AND IT'S TIME TO HAVE THE COMPANIONSHIP EXEMPTION
REGULATIONS TO

THE FAIR LABOR STANDARDS ACT UPDATED SO THAT THEY REFLECT A
MORE, THE EXTRAORDINARY GROWTH THAT WE'VE SEEN IN THIS
INDUSTRY.

WE WOULD ALSO LIKE TO SEE, THROUGH THE BURROW OF LABOR
STATISTICS, MUCH BETTER EMPLOYMENT STATISTICS ON THE HOME
AND

COMMUNITY-BASED WORK FORCE.

IN CALIFORNIA, AN EXAMPLE, THE BLS REPORTED IN 1998 THERE
WERE

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ABOUT 37,000 PEOPLE WHO WERE SERVING AS PERSONAL CARE AND
HOME

HEALTH AIDES STATEWIDE -- NATIONWIDE -- STATEWIDE, EXCUSE
ME.

BUT IN FACT THERE ARE CLOSE TO 200,000 INDIVIDUALS WORKING
IN

THE IN HOME SUPPORTIVE SERVICES PROGRAM PROVIDING PERSONAL
CARE
SERVICES.

THERE ARE SEVERAL STATES THAT DO NOT EVEN BOTHER TO REPORT
STATISTICS.

AND I WON'T NAME THEM, BUT THERE ARE SEVERAL THAT WE THINK
COULD

JOIN IN A NATIONAL EFFORT TO COLLECT DATA, NOT ONLY ON HOW
MANY

ARE PROVIDING THESE SERVICES, HOW MANY WILL BE NEEDED, WHAT
THE

A
TURNOVER AND RETENTION RATE IS, ALL GOOD ISSUES THAT WE NEED
LOT BETTER INFORMATION ABOUT.
TO THE DEPARTMENT OF HEALTH AND HUMAN SERVICES, OTHER PEOPLE
BASED
HAVE MENTIONED THE NEED TO EXPAND THE HOME AND COMMUNITY-
WAIVERS.
WE THINK STEPS SHOULD BE TAKEN PARTICULARLY IN LOOKING AT
DEVELOPING A MORE, A BROADER APPROACH TO BUDGET NEUTRALITY
REQUIREMENTS FOR PEOPLE GAINING ACCESS TO THOSE SERVICES.
AT
WE THINK THAT THERE SHOULD DEFINITELY -- WE SHOULDN'T LOOK
COMMINGLING OF FUNDS AS A DIRTY WORD IN THIS SETTING.
PEOPLE
WE SHOULD THINK ABOUT SAVINGS, NOT JUST TO MEDICAID WHEN
SETTING,
ARE GETTING SERVICES IN THE HOME AND COMMUNITY-BASED
PROGRAMS
BUT ALSO TO MEDICARE, TO THE TAX SYSTEM, AND TO OTHER
AS WELL.
OF
TO THE SOCIAL SECURITY ADMINISTRATION, I WOULD ASK FOR A LOT
THOUGHT AND CAREFUL ATTENTION BEING PAID TO WHO'S ALLOWED TO
62
AS
CONTRIBUTE TO THE SOCIAL SECURITY SYSTEM AS THEY'RE WORKING
PAID FAMILY MEMBERS.
SYSTEM,
PEOPLE ARE CURRENTLY RESTRICTED FROM CONTRIBUTING TO THE
AND THEY'RE THEREFORE UNABLE TO BUILD A RETIREMENT FUND.
AND FINALLY, WE WOULD LOOK FOR BETTER INTERAGENCY
COMMUNICATION

AND ACCOUNTABILITY FOR PROBLEM SOLVING IN THE AREA OF WORK
FORCE
DEVELOPMENT.
AND WE WOULD SPECIFICALLY RECOMMEND THAT LABOR ORGANIZATIONS
BE
INCLUDED IN, AT THE TABLE WHEN THE COUNCIL ON COMMUNITY
LIVING,
WHICH WAS PROPOSED BY THE EXECUTIVE ORDER, SITS DOWN TO
FOCUS ON
HOME AND COMMUNITY-BASED WORK FORCE DEVELOPMENT ISSUES.
THANK YOU VERY MUCH.
I APPRECIATE IT.

>> LADIES AND GENTLEMEN, THANK YOU VERY MUCH.
I WOULD LIKE TO ASK THE NEXT FOUR PEOPLE PROVIDING TESTIMONY
TO
PLEASE COME DOWN TO THE FRONT.

AND MR. KING, WE WILL NOW GO TO YOU PLEASE.
>> MY NAME IS BERNIE KING.
I REPRESENT PEOPLE SUPPORT NETWORK.
I LIVE IN NEW JERSEY.

THANK YOU FOR LETTING ME COME TODAY TO TALK ABOUT VALUES IN
THE
COMMUNITY AND INDEPENDENT LIVING.
WHEN I WAS YOUNG, I WAS PLACED IN AN INSTITUTION BECAUSE MY
MOTHER WAS AN UNABLE TO LOOK AFTER ME.
I HAVE CEREBRAL PALSY.
SINCE THEN I'VE LIVED IN OTHER PLACES.

IN OTHER PLACES THEY TOLD ME WHAT TO DO AND WHAT NOT TO DO.
AND FOR ME THAT WASN'T LIVING A GOOD LIFESTYLE.

INDEPENDENT

NOW I LIVE IN THE COMMUNITY, AND I'M LEARNING TO BE

AND LIVE MY OWN LIFE.

BUT I STILL HAVE SOME BARRIERS IN THE COMMUNITY.

THE

THEY ALWAYS SAY I'M ONLY GOING TO HAVE SO MANY HOURS A DAY,

GOVERNMENT.

DAY

THE GOVERNMENT SAYS I'M ONLY GOING TO HAVE SO MANY HOURS A

FOR HELP.

I NEED MORE HELP WITH SOME OTHER THINGS.

I NEED HELP COOKING, CLEANING.

I GO TO THE DOCTOR.

AND I VISIT OTHER FRIENDS.

AND I NEED HELP WITH THESE OTHER THINGS LIKE WHAT I'M DOING

TODAY.

TRY

I'VE BEEN WORKING FOR A LONG TIME WITH MEDICAID FOR THEM TO

TO GET THE HELP I NEED SO THAT I COULD BE INDEPENDENT.

I AM THE SAME PERSON THAT I WAS IN THE INSTITUTION.

THAT

IT WOULD MAKE ME VERY, VERY HAPPY TO RECEIVE THE SAME HELP

COMMUNITY

I HAD IN THE INSTITUTION THAT I COULD HAVE OUT IN THE

SO I COULD LIVE MY LIFE JUST LIKE EVERYBODY ELSE OUT IN THE

COMMUNITY.

I THANK YOU VERY MUCH TODAY.

>> THANK YOU VERY MUCH, MR. KING.

MR. WILLIAMS PLEASE.

>> CAN YOU HEAR THIS?

CAN YOU HEAR THIS?

CEREBRAL

I AM BOB WILLIAMS, A SENIOR POLICY ADVISOR AT UNITED

PALSY HERE IN WASHINGTON.

OF

FOR THE RECORD, I ALSO HELD TWO POSITIONS UNDER SECRETARY
SHALLALA DURING THE CLINTON YEARS, FIRST AS THE COMMISSIONER

THE ADMINISTRATION ON DEVELOPMENTAL DISABILITIES AND THEN
HEADING ITS OFFICE ON DISABILITY, AGING, AND LONG-TERM CARE
POLICY.

YOU

WE APPRECIATE THE OPPORTUNITY TO PROVIDE BRIEF INPUT BEFORE

NOW, AND I WILL SUBMIT WRITTEN COMMENTS AS WELL.

LIKE YOU I GOT UP THIS MORNING AT BREAKFAST, WHEN TO THE
BEDROOM, SHOWERED, SHAVED, DRESSED, AND STARTED MY DAY ALL
PRETTY MUCH WITHOUT GIVING IT A SECOND THOUGHT.

A

I'M ABLE TO DO THIS BECAUSE I AM EXTREMELY FORTUNATE TO HAVE

WIFE WHO IS THERE EVERYDAY, BOTH IN THE MORNING AND AGAIN AT
NIGHT TO LEND ME A HAND WHEN I NEED IT THE MOST.

THOUSANDS

BUT THIS MORNING, LIKE EVERY OTHER MORNING, THERE WERE

OUT OF

OF PEOPLE WITH DISABILITIES WHO WOKE UP AND WANTED TO GET

THEM.

BED BUT COULDN'T BECAUSE THERE WAS NO ONE THERE TO HELP

MOREOVER, MANY WERE PROBABLY UP HALF THE NIGHT WORRYING THIS
MIGHT HAPPEN BECAUSE, FRANKLY, IT HAS SO MANY TIMES BEFORE.

SIMPLE

WHILE MANY FACTORS CONTRIBUTE TO THIS, THE MAIN ONE IS

ECONOMICS BECAUSE, REGARDLESS OF THE STATE OUR REGION, MOST

JOB

COMMUNITY-BASED SERVICES WORKERS ARE EXPECTED TO DO THEIR

OTHER

AT POVERTY LEVEL WAGES OFTEN WITHOUT HEALTH COVERAGE OR

CAREER

EMPLOYEE BENEFITS AND WITH LITTLE TO NO OPPORTUNITY FOR A

65

ADVANCEMENT.

THESE

NOT SURPRISINGLY, THERE IS AN EVER INCREASING SHORTAGE OF

OVERTIME.

WORKERS, AND THOSE WHO DO REMAIN ARE FORCED TO WORK

LATE

THIS RESULTS IN TURNOVER RATES OF 100% AMONG MANY PROVIDER AGENCIES, INCREASED INCIDENCES OF ABUSE AND NEGLECT, AND COUNTLESS INCIDENCES WHEN PEOPLE WITH DISABILITIES ARE LEFT, OFTEN IN THEIR OWN WASTE, BECAUSE THEIR ATTENDANTS SHOW UP

THAT DAY OR NOT AT ALL.

CRISIS

THE FUTURE OF COMMUNITY-BASED SERVICES AND THE VERY LIVES OF MILLIONS OF PEOPLE WITH SIGNIFICANT DISABILITIES THEREFORE HINGES ON OUR ABILITY TO BEGIN TO REMEDY THIS NATIONAL

IMMEDIATELY.

SERVICE

TO THEIR CREDIT, SEVERAL STATES HAVE USED THEIR OWN FUNDS TO CREATE A LIVING WAGE FOR SOME MEDICAID COMMUNITY-BASED

WORKERS AND GREATER ACCESS TO HEALTH CARE COVERAGE.

IT'S TIME THAT THE FEDERAL GOVERNMENT STARTS TO PROVIDE SOME LEADERSHIP AND ADDITIONAL RESOURCES OF ITS OWN.

SHOW

THERE ARE THREE THINGS THAT THE ADMINISTRATION COULD DO TO

SOME LEADERSHIP IN THIS REGARD.

AGING
WORKERS.
MAKE

FIRST, WORK WITH CONGRESS, GOVERNORS, THE DISABILITY AND
COMMUNITIES TO FIND WAYS TO INCREASE EARNINGS OF THESE
IF WE TRULY VALUED PEOPLE WITH DISABILITIES BEING IN THE
AMERICAN COMMUNITY, WE MUST VALUE AND COMPENSATE THOSE WHO
IT POSSIBLE.
SECOND, SENATOR DURBIN HAS DRAFTED A BILL ENTITLED, THE CARE
GIVER ACCESS TO INSURANCE ACT THAT WOULD EXTEND BASIC HEALTH

66

TO
APPROACH TO
NATION
ACHIEVE

COVERAGE TO COMMUNITY SERVICES WORKERS AND THOSE IN RELATED
FIELDS.
SUPPORT THE BILL OR PROPOSE AN EQUALLY EFFECTIVE ALTERNATIVE
IT.
AND FINALLY, THE ADMINISTRATION SHOULD TAKE THE SAME
GUARANTEEING EQUAL ACCESS TO COMMUNITY SERVICES.
EITHER SUPPORT THE BILL IN ITS CURRENT FORM OR GIVE THE
AN ADA ANNIVERSARY PRESENT BY PROPOSING OTHER REFORMS TO
THE SAME AIM BY JULY 26TH OF NEXT YEAR.

THANK YOU.

>> THANK YOU VERY MUCH, MR. WILLIAMS.

MS. TAYLOR, WE TURN TO YOU PLEASE.

>> HI. MY NAME IS SUSAN TAYLOR, AND I'M AN OCCUPATIONAL
THERAPIST, PRACTICING AT THE REHABILITATION INSTITUTE OF
CHICAGO
IN THE SEATING AND MOBILITY CLINIC.

50% OF WE HAVE AN ACTIVE CASELOAD OF ABOUT 1,000 CLIENTS, 40% TO
WHOM RELY ON MEDICARE.
OTHER I'M HERE TODAY TO ASK YOUR HELP, ON BEHALF OF MYSELF AND
CLINICIANS, BUT MOST IMPORTANTLY ON BEHALF OF THE MEDICARE
CURRENT BENEFICIARY THAT WE SERVE WHO ARE BEING UNFAIRLY HURT BY
CMS AND POLICIES.
CONDUCTING A I AM AWARE THAT A NUMBER OF AGENCIES ARE CURRENTLY
REVIEW TO DETERMINE IF THEY NEED TO MODIFY ANY OF THEIR
POLICIES OR PROCEDURES TO ELIMINATE BARRIERS THAT MAY EXIST WHICH
PREVENT PEOPLE WITH DISABILITIES ACCESS TO COMMUNITY SERVICES.
EXIST I WOULD LIKE YOU TO KNOW THAT THESE BARRIERS DO IN FACT
67
UNDER MEDICARE PART B, FOR DURABLE MEDICAL EQUIPMENT.
I, AS AN OCCUPATIONAL THERAPIST, INCORPORATE BEST PRACTICE
GUIDELINES AS OUTLINED BY THE AMERICAN OT ASSOCIATION, AND
TO MY CLINICAL PRACTICE.
THIS MEANS I EVALUATE A CLIENT, WORK WITH THE CLIENT TO
DETERMINE THEIR NEEDS ARE, AND THEN LOOK AT MATCHING THE
CLIENTS NEEDS TO SPECIFIC PIECES OF DURABLE MEDICAL EQUIPMENT,
HOPEFULLY THAT WILL HELP THEM ACHIEVE A HIGH LEVEL OF INDEPENDENCE IN
THE COMMUNITY.

FOR
HOWEVER, CURRENT MEDICARE POLICY CREATES A CLINICAL DILEMMA
MYSELF AND OTHER CLINICIANS AS WELL.
SPECIFICALLY, WE HAVE TO CHOOSE BETWEEN OUR PROFESSIONAL
EXPERIENCE AND ETHICAL OBLIGATIONS THAT WE HAVE TO OUR
CLIENTS
TO MAKE THE MOBILITY DEVICE RECOMMENDATIONS FUNCTIONAL FOR
THEM
OR MAKE RECOMMENDATIONS THAT WILL SATISFY THE MEDICARE
LIMITATIONS ON MOBILITY DEVICE COVERAGE.
THOSE ARE THE TWO DECISIONS.
THE CHOICE IS VERY STARK.
THERE ARE VERY CLEAR DIFFERENCES BETWEEN THE DEVICES I WOULD
PREFER TO RECOMMEND VERSUS WHAT I CAN RECOMMEND UNDER
CURRENT
MEDICARE GUIDELINES.
THAT
IF I FOLLOW BEST PRACTICES, THEN I WILL RECOMMEND DEVICES
BE
WILL SUPPORT THE HIGHEST LEVEL OF INDEPENDENCE BUT MAY NOT
ON
AFFORDABLE TO THE PERSON, SHOULD THEY CHOOSE TO PURCHASE IT
THEIR OWN.
I AM
IF I TAILOR MY RECOMMENDATION TO CURRENT MEDICARE POLICIES,
LIMITED TO RECOMMENDING EQUIPMENT WHICH WILL ONLY ALLOW THE
CLIENT TO GET AROUND WITHIN THE FOUR WALLS OF THEIR HOME
ONLY.
MEDICARE POLICY SHOULDN'T FORCE SUCH A CHOICE ON PEOPLE.
PUBLIC POLICIES SOMEHOW COMPLEMENT EACH OTHER AND STRIVE
TOWARD

THE SAME GOALS.

MEDICAL HCFA, WHICH IS NOW CMS, ISSUED INSTRUCTIONS TO THE DEMARK
MEDICAL DIRECTORS, THAT THEY SHOULD CONSIDER ONLY THE
NEEDS FOR A DEVICE THAT ARISES WITHIN THE FOUR WALLS OF THAT
PERSON'S HOME.

GROCERY SO THEREFORE ACTIVITIES OF INDEPENDENT LIVING, SUCH AS
TAKING SHOPPING, GOING TO CHURCH, GOING TO VISIT YOUR FRIENDS,
YOUR SON TO SCHOOL, ARE CRITICAL COMPONENTS OF INDEPENDENCE
OBVIOUSLY, AND YET THESE ACTIVITIES ARE PERFORMED OUTSIDE
THE FOUR WALLS OF YOUR HOME.

CURRENT THEY ARE NOT CONSIDERED NECESSARY ACTIVITIES UNDER THE
QUALIFICATION REQUIREMENTS.

AND I BELIEVE THAT THE CURRENT INTERPRETATION USED BY THE CMS
THE DEMARKS IS SIGNIFICANTLY LIMITING ACCESS TO COMMUNITY
SERVICES FOR PEOPLE WITH DISABILITIES.

THAT AND I AM REQUESTING THAT THIS PANEL MAKE A RECOMMENDATION
CMS AND THE DEMARKS CEASE USING THIS VERY RESTRICTIVE
MEDICAL INTERPRETATION THAT LIMITS ACCESS TO APPROPRIATE DURABLE
EQUIPMENT AND THAT ALL COVERAGE POLICIES BE REVIEWED TO
ELIMINATE THE PREJUDICE THAT EXISTS WITH THAT CURRENT
INTERPRETATION.

>> MR. KOSINSKI, WE TURN TO YOU, PLEASE.

>>> GOOD MORNING.

AND I THANK THE PANEL FOR THIS OPPORTUNITY TO VOICE OUR CONCERNS

OFFER OUR ASSISTANCE TO THE PRESIDENT IN CARRYING OUT THE SPIRIT

OF THE NEW FREEDOM INITIATIVE.

THE NEW FREEDOM INITIATIVE IS DESIGNED TO ENSURE THAT ALL SKILLS AMERICANS WITH DISABILITIES HAVE THE TOOLS TO USE THEIR

AND MAKE MORE OF THEIR OWN CHOICES.

ARE BUT THE NEW FREEDOM INITIATIVE'S KEY COMPONENTS AND TITLES

NOT EXACTLY NEW TO THE PEOPLE WHO HAVE WORKED, FOR THE LAST TWELVE YEARS, UNDER THE MANDATE OF THE TECH ACT.

TECH I AM HERE TODAY AS A REPRESENTATIVE OF THE ASSOCIATION OF ACT PROJECTS.

TECHNOLOGY THE TECHNOLOGY RELATED ASSISTANCE FOR INDIVIDUALS WITH DISABILITIES ACT OF 1988 WAS PASSED BY CONGRESS TO INCREASE ACCESS TO AVAILABILITY OF AND FUNDING FOR ASSISTIVE

THROUGH STATE EFFORTS AND NATIONAL INITIATIVES.

EXPERIENCE THE STATE AT PROJECTS HAVE A WEALTH OF KNOWLEDGE AND

RELATED TO THE SERVICES, SUPPORTS, AND SYSTEMS THAT WILL RAISED BY DETERMINE OUR COUNTRY'S RESPONSE TO SOME BIG QUESTIONS

THE NEW FREEDOM INITIATIVE:

HOW DO WE ADDRESS THE NEEDS AND EXPECTATIONS OF THE AGING POPULATION?

HOW WILL PEOPLE WITH DISABILITIES WHO WANT TO WORK BECOME EMPLOYED?

CARE?

HOW WILL WE ENSURE THAT ALL CITIZENS HAVE ADEQUATE HEALTH

HOW DO WE ENSURE THAT ALL CHILDREN ARE GETTING A QUALITY

70

EDUCATION?

IN

HOW DO WE ENSURE THAT REVOLUTIONARY NEW TECHNOLOGIES WON'T

SOME

EFFECT CLOSE DOORS OF OPPORTUNITY RATHER THAN OPEN THEM FOR

PEOPLE?

OUR

THE STATE AT PROJECTS PLAY A VITAL ROLE IN MAKING SURE THAT

NATION CONTINUES TO EVOLVE INTO A FULLY INCLUSIVE SOCIETY.

TECHNOLOGY

STATE AT PROJECTS KNOW HOW TO FACILITATE ASSISTIVE

FISCALLY

ACCESS IN WAYS THAT ARE BOTH CONSUMER RESPONSIVE AND

RESPONSIBLE.

SPECIFICALLY

THE STATE AT PROJECTS ARE THE ONLY PROGRAMS FUNDED

OR

TO ENSURE THAT PEOPLE WITH DISABILITIES, REGARDLESS OF AGE

OF

DISABLING CONDITION HAVE ACCESS TO TECHNOLOGY DEVICES AND

SERVICES THEY NEED TO BE INDEPENDENT AND PRODUCTIVE MEMBERS

SOCIETY.

OF

NOW, WHETHER AGENCIES OR ORGANIZATIONS DUPLICATE THE RANGE

THIS

SERVICES AND SUPPORTS OFFERED BY STATE AT PROJECTS, WITHOUT

NATIONAL INFRASTRUCTURE THERE WILL BE UNBRIDGEABLE GAPS IN

THE

ACCESS TO ASSISTIVE TECHNOLOGY, DEVICES, SERVICES THROUGHOUT

COUNTRY.
TERRITORY THE PEOPLE, THE PRIORITIES, AND POLITICS IN EACH STATE
ARE DEvised -- OR AS DIVERSE AS OUR NATION IS BIG.
CHALLENGES OVER THE PAST TWELVE YEARS AT PROJECTS HAVE OVERCOME
AND GAINED VALUABLE UNDERSTANDING IN CONNECTING PEOPLE WITH
TECHNOLOGY, EVEN IN THE FACE OF GEOGRAPHIC, ATTITUDINAL, AND
FINANCIAL BARRIERS.
AND AS A RESULT, PEOPLE WITH DISABILITIES HAVE GREATER ACCESS TO

71

IN REALIZE MORE BENEFIT FROM TECHNOLOGY THAN AT ANY OTHER TIME
HISTORY.
THAT'S GOOD FOR THE ENTIRE NATION.
WORKING, WITH TECHNOLOGY MORE PEOPLE ARE LIVING INDEPENDENTLY,
AND PARTICIPATING IN SCHOOL, CONTRIBUTING TO THEIR NEIGHBORHOOD,
ENJOYING RECREATIONAL OPPORTUNITIES.
AS A IN SPITE OF THESE ACHIEVEMENTS AND WITH ALL OF THE ATTENTION
TECHNOLOGY IS GETTING FROM GOVERNMENT, BUSINESS AND SOCIETY
BENEFIT WHOLE, IT WOULD BE EASY TO ASSUME THAT EVERYONE COULD
FROM ASSISTIVE AND MAINSTREAM CAN BE -- AND WILL GET IT.
EXCUSE ME.
IT'S SIMPLY NOT SO.
ALTHOUGH STATE AT PROJECTS HAVE LED THE CHARGE TOWARD A MORE
ACCESSIBLE SOCIETY, THERE IS STILL MUCH WORK TO BE DONE TO

AND ENSURE THAT THOSE WHO DESIGN, CREATE, DISTRIBUTE, REGULATE,
FUND TECHNOLOGY DO SO WITH ALL USERS IN MIND.
EVERY STUDENT MUST MASTER TECHNOLOGY SKILLS IN ORDER TO
SUCCEED AND BE PRODUCTIVE.
IT IS ESSENTIAL THAT THE TECHNOLOGY USED IN OUR SCHOOLS
LEAVES NO ONE BEHIND.
BUT PREPARING TEACHERS TO INTEGRATE TECHNOLOGY INTO THE
CLASSROOM AND TRAINING EDUCATORS TO USE TECHNOLOGY TO
SUPPORT STUDENTS ARE FORMIDABLE TASKS.
PARENTS, STUDENTS, AND EDUCATORS ARE LOOKING FOR ASSISTANCE
TO IDENTIFY TECHNOLOGY SOLUTIONS THAT WILL GIVE THEM THE TOOLS
THEY NEED TO PARTICIPATE FULLY IN SCHOOL.

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THE STATE AT PROJECTS ASSIST LOCAL SCHOOL SYSTEMS, INCREASE
THEIR AT PURCHASING POWER BY NEGOTIATING DISCOUNT PRICES FOR
EDUCATIONAL TECHNOLOGY WITH VENDORS.
>> I'M SORRY TO INTERRUPT, BUT IF YOU COULD CONCLUDE PLEASE?
>> ALL RIGHT.
>> THANK YOU.
>> EVEN THOUGH THE STATE AT PROJECTS HAVE HAD SUCH A
COMMENDABLE HISTORY AND CAN BE MAJOR CORNERSTONES IN THE PRESIDENT'S NEW
FREEDOM INITIATIVE, THEY ARE ON THE VERGE OF TERMINATION.
UNLESS CONGRESS TAKES ACTION THIS YEAR, THE FIRST NINE OF
THE

STATE AT PROJECTS WILL NOT BE FUNDED IN 2002.
THE REST OF THE PROJECTS WILL FOLLOW THE SAME FATE BY 2004.
I'M HERE TO DRAW YOUR ATTENTION TO THIS FACT AS YOU BEGIN TO
PLOT YOUR STRATEGY FOR ACCOMPLISHING THE SPIRIT OF THE NEW
FREEDOM INITIATIVE.
I ASK YOU NOT TO ALLOW THE STATE AT PROJECTS TO SUNSET BUT
INCORPORATE THEM IN THIS PLAN.
WE KNOW THE ISSUES AND THE PEOPLE WHO WILL BENEFIT
FROM THE INITIATIVE, AND WE ARE READY AND IN PLACE TO BEGIN
TODAY.
THANK YOU.
>> THANK YOU VERY MUCH, LADIES AND GENTLEMEN, FOR YOUR
TESTIMONY.
I WOULD LIKE TO INVITE THE NEXT FOUR INDIVIDUALS WHO WILL BE
PROVIDING TESTIMONY TO PLEASE COME DOWN.
AND MR. LOPEZ, WE'LL MOVE TO YOU, PLEASE.

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AND

>> DISTINGUISHED PANEL, MY FELLOW PEERS, CONCERNED CITIZENS,
FAMILY MEMBERS, MY NAME IS JESSIE LOPEZ,
AND I'M REPRESENTING THE POST POLIO SURVIVORS.
I'M EXECUTIVE DIRECTOR OF THE POST POLIO FOUNDATION IN
CALIFORNIA, HOME OF THE WORLD CHAMPION LAKERS.
(LAUGHTER)
POLIO SURVIVORS ARE THE FIRST MAJOR GROUP OF PEOPLE WITH
DISABILITIES TO BE INTEGRATED INTO AMERICAN SOCIETY.
WE FACE THE CHALLENGES OF LIFE FROM THE BEGINNING.

NEW
NOW TWO OUT OF THE THREE POLIO SURVIVORS ARE EXPERIENCING
PROBLEMS.
MUSCLE
TO SURVIVORS OF THE ONSIGHT OF POLIO, THE RESURRECTION OF
WEAKNESS.
FATE.
NEUROLOGICAL DEFECTS FOR A SECOND TIME IS A CRUEL TWIST OF
POLIO SURVIVORS HAVE SPENT THEIR LIFE TRYING TO LIVE, QUOTE,
UNQUOTE, NORMAL LIVES.
WE WORKED, WENT TO SCHOOL THE BEST WE COULD.
NOW WE MUST USE BRACES, WHEELCHAIRS, THAT WE ONCE DISCARDED
ALMOST THIRTY YEARS AGO.
FRIGHTENING
WE MUST REDUCE OUR PHYSICAL ACTIVITY WHICH IS BOTH
AND DIFFICULT FOR US.
ALTOGETHER.
MANY OF US HAD TO CHANGE OUR JOBS AND HAVE LOST JOBS
AGAIN
MANY AMERICANS WITH POST POLIO SYNDROME WOULD LIKE TO WORK
OR CONTINUE WORKING.
FROM
OUR GREATEST CHALLENGE IS NOT THE JOB ITSELF BUT GETTING
THE JOB, GETTING FROM HOME TO THE JOB.
74
NOT
INSURANCE COMPANIES WILL NOT PAY FOR CHAIR LIFTS. THEY WILL
PAY FOR RAMPS.
DEVICES TO
THEY WILL NOT PAY FOR BATTERIES TO OPERATE MECHANICAL
GET TO WORK.
THESE ARE VERY EXPENSIVE AND COST A LOT OF MONEY.

POLIO SURVIVORS HAVE BEEN DISCRIMINATED AGAINST BY TAX RETURNS.

THINGS MOST OF US CAN'T DO OUR OWN LAWN, WE CAN'T DO A LOT OF OURSELVES, SO WE HAVE TO PAY THESE THINGS.

EXPENSES, AND IF YOU LOOK AT YOUR TAX RETURN, TO CLAIM MEDICAL IT'S 7.5% OF YOUR AGI, WHICH MOST PEOPLE CAN'T QUALIFY FOR. SO IT'S VERY EXPENSIVE TO BE -- TO HAVE A DISABILITY.

SYNDROME THE GENERAL CAUSE OR THE GENERAL SYMPTOM OF POST POLIO IS A FLU-LIKE FATIGUE.

WE HAVE A LOT OF FATIGUE.

WE NEED LIFESTYLE CHANGES.

WE CAN'T DO WHAT WE USED TO BE DOING.

WE NEED REST PERIODS, AND EVEN SOME OF US NEED DAYTIME NAPS.

CONVENIENCE MORE AMERICANS ARE WORKING AT HOME, AND THIS IS A FOR THEM.

HOME. BUT THIS WOULD BE A REVOLUTION FOR US, IF WE COULD WORK AT WE NEED FUNDS TO BUY EQUIPMENT AND TRAIN US ON COMPUTERS AND TELECOMMUNICATION SKILLS WITHOUT ANY KIND OF INCOME LIMITATION

AND TO TO PROVIDE THE OPPORTUNITY FOR US TO MAKE OUR OWN CHOICES LEAD LIVES OF GREATER INDEPENDENCE.

POLIO WE NEED HELP FROM THE MEDICAL COMMUNITY TO HELP DIAGNOSIS IN ITS EARLY STAGES.

AND WE NEED TO FIND THE CAUSES AND THE SYMPTOMS, THE PREVALENCE,
EVEN TREATMENT OF POST POLIO SYNDROME.
WE NEED FUNDS TO ESTABLISH REGIONAL CENTERS OR NETWORKS OF
SYNDROME. PROVIDERS WITH EXPERTISE IN THE ASPECTS OF POST POLIO
AND I DON'T WANT TO OFFEND ANYONE ON THE PANEL, BUT WE NEED
PEOPLE WITH DISABILITIES TO MAKE MAJOR DECISIONS FOR PEOPLE
WITH DISABILITIES.
OUR GOAL AT THE POST POLIO FOUNDATION IS TO INCREASE THE
AWARENESS AND KNOWLEDGE OF THE COMMUNITY.
THEY NEED TO REALLY UNDERSTAND WHAT POST POLIO SYNDROME IS.
WE NEED TO GATHER AND SHARE ACCURATE INFORMATION TO
GOVERNMENT AGENCIES TO INCREASE PUBLIC AWARENESS OF POST POLIO
SYNDROME, PROVIDE MEDICAL OUTREACH PROGRAMS REGARDING POST POLIO
SYNDROME TO SECURE MEDICAL DEVICES NOT COVERED BY PRIVATE INSURANCE
AGENCIES, PROVIDE POST POLIO SUPPORT GROUPS WITH
READJUSTMENTS IN LIFESTYLE, SUCH AS OCCUPATIONAL CHANGE AS I MENTIONED
BEFORE.
AND SOME OF US HAVE TO STOP WORKING ALTOGETHER.
INDEPENDENCE IS WHAT WE WANT.
AND WITH YOUR CONCERN AND HELP, WE CAN GET THIS DONE.
>> THANK YOU MR. LOPEZ.
MS. ANTHONY, PLEASE.
>> GOOD MORNING.
THANK YOU.
GOOD MORNING.

I AM JANE ANTHONY SPEAKING ON BEHALF OF THE VOICE OF THE

76

RETARDED.

I AM THE MOTHER OF JASON KINSLER, A RESIDENT OF NORTHERN VIRGINIA TRAINING CENTER IN FAIRFAX, VIRGINIA.

JASON HAS PROFOUND MENTAL RETARDATION.

HE 26 YEARS OLD, HAS A MENTAL AGE OF SIX TO NINE MONTHS, AND HAS ANGIILMEN'S SYNDROME.

SENSE
ALTHOUGH HE HAS THE MIND OF A BABY, HE IS MOBILE, HAS NO OF DANGER, IS STRONG, AND HAS PICA, WHICH MEANS HE EATS INAPPROPRIATE ITEMS.

I'M ALSO JASON'S ADVOCATE.

I AM THE IMMEDIATE PAST PRESIDENT OF PARENTS AND THE INSTITUTIONALIZED RETARDED OF VIRGINIA AND A BOARD MEMBER OF VOICE OF THE RETARDED.

MENTAL
VOR IS A NATIONAL ORGANIZATION REPRESENTING PEOPLE WITH RETARDATION AND THEIR FAMILIES.

THE
WE ARE THE ONLY NATIONAL ORGANIZATION ACTIVELY SUPPORTING WIDE VARIETY OF CARE OPTIONS NEEDED FOR PEOPLE WITH MENTAL RETARDATION, INCLUDING OWN HOME, ALL COMMUNITY-BASED SUPPORTS,
AND ICFMR'S.

CARE:

ONE, THE LACK OF ACCESS TO QUALITY HEALTH CARE INCLUDING MEDICAL, DENTAL, THERAPEUTIC AND RECREATIONAL SERVICES; AND TWO,

D.C.,

THE LACK OF QUALITY CARE WHICH HAS BEEN DOCUMENTED HERE IN

ON THE WEST COAST, AND MANY PLACES IN BETWEEN.

FIRST, TO IRRADICATE THE BARRIERS TO MEDICAL CARE, VOR

RECOMMENDS THE CENTER OF EXCELLENCE MODEL, THE MOST ADVANCED

77

MODEL.

IS

THE MOST ADVANCED MODEL OF THIS PROGRAM OF WHICH I AM AWARE

AT NORTHERN VIRGINIA TRAINING CENTER.

MORE MODEST PROGRAMS EXIST ACROSS THE COUNTRY.

BASED

THESE INITIATIVES DEMONSTRATE THAT ACCESS TO NEEDED HEALTH,
DENTAL, AND RELATED SERVICES BY PEOPLE RECEIVING COMMUNITY-

ALLOWING

RESIDENTIAL SUPPORTS COULD BE SUBSTANTIALLY IMPROVED BY

ACCESS TO THE PROFESSIONAL EXPERTISE AVAILABLE AT ICFMR.

DEVELOPMENT

VOR STRONGLY URGES HHS TO ACTIVELY SUPPORT ON-GOING

CONCERNING

OF CENTERS OF EXCELLENCE BY DISSEMINATING INFORMATION

THESE EMERGING PROGRAMS, AND MOST IMPORTANTLY, BY ENHANCING
THEIR FUNDING OPTIONS THROUGH MEDICAID.

VOR

SECOND, TO INSURE SAFE QUALITY CARE IN COMMUNITY SETTINGS,

RECOMMENDS DEVELOPING REALISTIC UNIFORM STANDARDS FOR CARE,

REPORTING EVENTS, ADDRESSING THE NEED FOR REALISTIC

REIMBURSEMENT RATES, REQUIRING LIVING WAGES AND STANDARD

ENHANCE

TRAINING FOR COMMUNITY-BASED REC SUPPORT STAFF WOULD ALL

THE QUALITY AND SAFETY OF COMMUNITY LIVING FOR PEOPLE WITH

MENTAL RETARDATION.

EFFORTS BY CMS, SUCH AS THE PROTOCOL, SHOULD BE EXPANDED AND ENHANCED.

WHILE THE OLMSTEAD DECISION CLEARLY ENDORSES COMMUNITY-BASED CARE FOR MOST PEOPLE WITH MENTAL RETARDATION, IT ALSO

CAUTIONS

AGAINST FORCING COMMUNITY OR HOME BASED CARE UPON THOSE WHO REQUIRE AND DESIRE ICFMR CARE.

AS FEDERAL AGENCIES CONSIDER BARRIERS TO COMMUNITY PLACEMENT,

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PLEASE DO NOT FORGET ABOUT PEOPLE LIKE MY SON WHO ARE THE MOST

VULNERABLE INDIVIDUALS, WITH SEVERE AND PROFOUND MENTAL RETARDATION, WHO ALSO SUFFER BEHAVIORAL AND OR MEDICAL CHALLENGES.

VOR IS PREPARED TO ACTIVELY PARTICIPATE IN FUTURE DISCUSSIONS OF

THESE ISSUES.

WE APPLAUD THE EFFORTS HERE TODAY AND URGE THAT THEY BE CONTINUED.

THANK YOU FOR LISTENING.

>> THANK YOU, MS. ANTHONY.

PLEASE, SIR.

>> GOOD MORNING.

MY NAME IS GERRY KASUNIC.

AND I AM THE DIRECTOR OF THE D.C. LONG-TERM CARE PROGRAM.

AND WE ARE GRANTED THROUGH THE AARP FOUNDATION.

WE HAVE SUBMITTED COMMENTS ON AUGUST 26TH TO THE DEPARTMENT OF

HEALTH AND HUMAN SERVICES.

AND WE HAD SEVEN COMMENTS THAT WE MADE.

FOCUS

AND SEEING THAT WE ONLY HAVE THREE MINUTES, I WILL ONLY

ROUGHLY ON FOUR.

FIRST AND FOREMOST, THE DISTRICT OF COLUMBIA IS ACTUALLY
COMMENTED IN THIS.

THE

AND THESE PROBLEMS THAT WE HAD IN THE DISTRICT, ACCORDING TO

REGIONAL STATE DIRECTORS THAT I'VE SPOKEN WITH, ARE ACTUALLY
NATIONAL.

HERE

SO IT WOULD BE SOMETHING THAT ALL OF THE DEPARTMENT HEADS

79

SHOULD TAKE A LOOK AT, WITHIN THE DISTRICT AS WELL AS WITHIN
THEIR REGIONS.

THAT

THE DISTRICT OF COLUMBIA IS A UNIQUE GEOGRAPHIC ENVIRONMENT

DISTRICT'S

IMMEDIATELY PLACES LIMITATIONS ON ELDERLY AND DISABLED
INDIVIDUALS CHOICES OF HOUSING, JUST SIMPLY BY THE

PHYSICAL SIZE.

WAIT

BECAUSE OF THESE LIMITATIONS, INDIVIDUALS CURRENTLY MUST

TWO OR THREE YEARS ON HOUSING LISTS BEFORE THEIR PLACEMENTS.

THEREFORE, THE DISTRICT GOVERNMENT MUST BE WILLING TO

FINANCIALLY BE ABLE TO COMMIT TO A LARGE SCALE INVESTMENT IN

CATERING

DEVELOPING HOUSING FOR THE ELDERLY AND DISABLED, WITH

SERVICES FOLDED INTO THEIR AGREEMENTS.

TO SECOND, THE DISTRICT OF COLUMBIA HAS NOT YET PREPARED ITSELF
MEET THE NEEDS OF TRANSITIONING INDIVIDUALS WHO REQUIRE
INTENSIVE, 24 HOUR SERVICES INCLUDED INTO THEIR PREEEXISTING
HOUSING PLANS.
EVEN AT THIS CURRENT DATE, THE DISTRICT OF COLUMBIA ONLY HAS
MEDICAID HALF OF THE ELDER POPULATION ELIGIBLE FOR THE ORIGINAL
WAIVER, DUE TO THE LACK OF COMMUNITY SERVICES AND HOUSING.
SINCE THE ELDERLY ARE NOT RECEIVING THE STANDARD COMMUNITY
THAT SERVICE SUPPORTS, THE D.C. LONG-TERM CARE PROGRAM BELIEVES
SOME INDIVIDUALS WILL NEED INTENSIVE SUPPORTS IN THEIR
OR COMMUNITIES SO THEIR EVOLVING HOSPITALIZATIONS MAY NOT BE --
MAY BE KEPT AT A MINIMUM, THUS SAVING THE DISTRICT'S
MEDICAID AND THE HIGH COST OF EMERGENCY HOSPITALIZATIONS AND SERVICES
THAT SOLIDIFY IN THEIR COMMUNITY.

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LIMITED TO SUCH COMMUNITY SUPPORTS SHOULD BE INCLUDED BUT NOT BE
CRISIS RESPONSE TEAMS, RESOURCE
COORDINATORS, AND EMERGENCY BEDS STRATEGICALLY LOCATED
THROUGHOUT THE CITY.
THIRD, THE DISTRICT DOES NOT HAVE A STANDARDIZED -- EXCUSE
ME,
THE DISTRICT DOES NOT HAVE A STANDARDIZED DISCHARGE PLAN TO
VICE TRANSITION INDIVIDUALS FROM INSTITUTIONS TO COMMUNITIES AND
VERSA.

SINCE THE DISTRICT OF COLUMBIA'S DEPARTMENT OF HEALTH AND
MEDICAID OFFICES DO NOT REQUIRE A DISCHARGE PLAN, IT IS
ALMOST
IMPOSSIBLE TO TRACK, IMPLEMENT, AND ASSESS INDIVIDUAL NEEDS
OR
SET UP PROPER COMMUNITY-BASED SERVICES TO ENSURE SUCCESSFUL
PLACEMENT.
THE PROVIDERS AND INDIVIDUALS ENTERING INTO THE NEW MEDICAID
WAIVER SYSTEM SHOULD PROVIDE A SIMPLE, BUT YET FLEXIBLE,
PLAN TO
COMMUNITY-BASED AGENCIES, ENSURING THAT QUALITY AND ANY
SERVICES
PROVIDED BY A FACILITY SHOULD BE MADE AVAILABLE BY THE
COMMUNITY
PER INDIVIDUALS' NEEDS.
FINALLY, PROBLEMATIC TO THE NATION, AND NOT JUST TO THE
DISTRICT
OF COLUMBIA, IS A SEVERE SHORTAGE OF HEALTH CARE WORKERS.
LOW WAGES, POOR OR NO BENEFITS, OR LACK OF CAREER
OPPORTUNITIES
ARE MAJOR BARRIERS TO RECRUIT STAFF AND MIDDLE MANAGERS WHO
PROVIDE SERVICES TO THE ELDERLY AND THE DISABLED.
THE DISTRICT, AS WELL AS THE FEDERAL GOVERNMENT, MUST
REALIZE
THAT PROFESSIONAL EDUCATION, TRAINING, AND CAREER
DEVELOPMENT IS
ESSENTIAL IN ORDER TO HAVE A SUCCESSFUL COMMUNITY-BASED
MODEL.

INTRODUCING SERVICES WITHOUT CAREER OPPORTUNITIES FOR
STAFFERS
AND PARAPROFESSIONALS WILL CREATE YET ANOTHER STAFF TO
RESIDENT

RATIO GAP, ENSURING FUTURE INSTABILITY AND POOR SERVICES.

THANK YOU.

>> JUST ONE ANNOUNCEMENT, PLEASE.

AFTER WE COMPLETE HEARING THE TESTIMONY FROM THE REMAINING
PEOPLE IN THE FRONT OF THE ROOM, WE WILL BE GOING
IMMEDIATELY

INTO THE OPEN MICROPHONE PERIOD.

WHAT I WOULD LIKE TO DO, THOSE OF YOU WHO HAVE SIGNED UP FOR
THE

OPEN MICROPHONE AND HOLDING CARDS ONE THROUGH EIGHT, IF YOU
WOULD PLEASE ASSEMBLE IN THE BACK OF THE ROOM SO THAT WE CAN
MOVE IMMEDIATELY TO THAT IN THE AGENDA.

MR. ROGERS, THANK YOU.

>> HI.

MY NAME IS JOSEPH ROGERS.

AND I AM A PERSON WITH A DISABILITY.

I HAVE A DIAGNOSIS OF BIPOLAR DISORDER.

AND I'M HERE ON BEHALF OF THE NATIONAL MENTAL HEALTH
CONSUMERS

SELF HELP CLEARINGHOUSE.

I'M THE EXECUTIVE DIRECTOR.

I WANT TO THANK THE PARTICIPATING FEDERAL DEPARTMENTS FOR
THIS

OPPORTUNITY TO SPEAK ON EXECUTIVE ORDER 13217, FULFILLING
THE

PROMISE TO THE AMERICANS WITH DISABILITY ACT.

IT'S EXTREMELY IMPORTANT.

I CONGRATULATE PRESIDENT BUSH ON HIS INITIATIVES IN THIS
AREA,

PARTICULARLY IN REGARD TO PROMOTING FULL ACCESS TO COMMUNITY

COURT LIFE THROUGH THE SWIFT IMPLEMENTATION OF THE U.S. SUPREME
DECISION IN OLMSTEAD.

I ALSO WANT TO THANK THE U.S. DEPARTMENT OF HEALTH AND HUMAN
SERVICES, MR. ALLEN AND FOLKS AT CENTER FOR MENTAL HEALTH
SERVICES, AND SAMHSA FOR ALL OF THEIR EFFORTS, PARTICULARLY
DR. ARON'S, THE NEW HEAD OF SAMHSA, OR HOPEFULLY THE NEW
HEAD OF SAMHSA -- HE'S BEEN NOMINATED BY CHARLES CURIE AND THE
OUTGOING ACTING HEAD, JOSEPH AUTRY -- FOR ALL OF THEIR WORK IN MENTAL
HEALTH AND HELPING TO GET THE STATES UP TO SPEED WHEN IT
COMES TO OLMSTEAD.

THE GOOD NEWS IS THAT PEOPLE WITH PSYCHIATRIC DISABILITIES
ARE NOT WAITING AROUND FOR THE FEDERAL GOVERNMENT TO EMBARK ON
THESE INITIATIVES THOUGH.

ALTHOUGH SUCH EFFORTS ARE GREATLY APPRECIATED, PEOPLE WITH
PSYCHIATRIC DISABILITIES ARE ALSO ORGANIZING ON THEIR OWN
BEHALF TO DEMAND THAT THEIR RIGHTS BE FULLY REALIZED UNDER THE
PROMISE OF THE ADA AND OTHER PROVISIONS OF THE CIVIL RIGHTS LAW.

PEOPLE IN PORTLAND OREGON, IN AUGUST OF 1999, APPROXIMATELY 450
WITH PSYCHIATRIC DISABILITIES FROM THE AROUND THE COUNTRY
ATTENDED THE NATIONAL SUMMIT OF MENTAL HEALTH CONSUMERS AND
SURVIVORS ORGANIZED BY THE NATIONAL MENTAL HEALTH CONSUMERS
SELF HELP CLEARINGHOUSE WITH THE HELP OF THE OREGON OFFICE OF
CONSUMER TECHNICAL ASSISTANCE.

IT WAS THE GOAL -- IT'S GOAL WAS TO DEVELOP CONSENSUS AROUND
ISSUES OF GREATEST CONCERN TO PEOPLE WITH PSYCHIATRIC
DISABILITIES AND TO CREATE ACTION PLANS FOR FUTURE WORK.

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WHICH THE UNIFYING PRINCIPLE WAS THE CONSTRUCTION OF A PLATFORM,
THE CONSUMER/SURVIVOR MOVEMENT CAN INFLUENCE THE NATIONAL
DEBATE.
ON ATTACHED TO MY TESTIMONY AND AVAILABLE THROUGH THE INTERNET
WWW.MH.SELFHELP.ORG IS THE COMPLETE RESULTS OF THAT WORK.
PARTICULARLY, I WANT TO TALK ABOUT THE ISSUES
RAISED IN THE FORCE AND COERCION PLANK.
IT IS IRONIC THAT THE GOVERNMENT SPENDS A HUGE AMOUNT OF
RESOURCES IN DISCUSSING HOW TO FULLY INTEGRATE PEOPLE WITH
THE DISABILITIES, PARTICULARLY PSYCHIATRIC DISABILITIES, INTO
AROUND COMMUNITY, WHILE AT THE SAME TIME EFFORTS ARE UNDERWAY
THE COUNTRY TO EXPAND FORCED TREATMENT.
DISCUSSIONS IN THE EXPANSION OF FORCED TREATMENT, INCLUDING INVOLUNTARY
OUTPATIENT COMMITMENT, IS ONE OF THE KEY AREAS OF
THE FORCE AND COERCION PLANK IN PORTLAND.
REPORTED THE GROUP TOOK A FIRM STAND AGAINST SUCH EXPANSION AND
OFF THE FOLLOWING VISION STATEMENT: WE WILL WORK TOWARD A
FUTURE WHERE ALL THE NEEDS OF A PERSON WITH A PSYCHIATRIC
DISABILITY CAN TRULY BE MET IN THE COMMUNITY GENTLY, AND
SUPPORTIVELY, AND HOLISTICALLY.

PEOPLE
BASICALLY, IN SUMMARY, ONE OF OUR GREATEST CONCERNS IS
CLOCK,
WITH PSYCHIATRIC DISABILITIES IS THE TURNING BACK OF THE
EMPHASIZE
THE DESIRE TO LOOK AT SOLUTIONS THAT ARE COERCIVE AND
THE INVOLUNTARY VERSUS THE VOLUNTARY.
WE ASK FOR YOUR SUPPORT TO MOVE FORWARD IN SUPPORTING SUCH
ACTIVITIES AS THE PROTECTION IN ADVOCACY PROGRAMS AND OTHER

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PROGRAMS THAT ASSURE THAT WE HAVE ACCESS TO THE COMMUNITY.
WE NEED THE SUPPORT.
FOR FURTHER INFORMATION, AGAIN, OUR WEBSITE IS
WWW.MHSELFHELP.ORG.
THANK YOU VERY MUCH.
THREE
>> MANY ROGERS, I WOULD LIKE TO THANK YOU AND THE OTHER
INDIVIDUALS WHO PROVIDED TESTIMONY.
THANK YOU VERY MUCH.

PROGRAMS THAT ASSURE THAT WE HAVE ACCESS TO THE COMMUNITY.
WE NEED THE SUPPORT.
FOR FURTHER INFORMATION, AGAIN, OUR WEBSITE IS
WWW.MHSELFHELP.ORG.
THANK YOU VERY MUCH.
THREE
>> MANY ROGERS, I WOULD LIKE TO THANK YOU AND THE OTHER
INDIVIDUALS WHO PROVIDED TESTIMONY.
THANK YOU VERY MUCH.
IT WOULD LIKE TO NOW ASK THE FIRST FOUR INDIVIDUALS FROM THE

OPEN MIC SESSION TO PLEASE COME UP TO THE FRONT AS WE WILL
CONTINUE WITH THE PUBLIC TESTIMONY SEGMENT.

THAT

BEFORE, MARTY, I GO TO YOU, IF YOU WOULDN'T MIND, I KNOW

DIAS,

THERE HAVE BEEN SEVERAL PEOPLE WHO HAVE JOINED US ON THE

AND I WOULD LIKE TO GIVE THEM THE OPPORTUNITY TO INTRODUCE
THEMSELVES PLEASE.

POLICY

>> I'M PAUL VAN DE WATER, ACTING DEPUTY COMMISSIONER FOR

AT THE SOCIAL SECURITY ADMINISTRATION.

AT

>> MY NAME IS DAWN HIVELY, AND I'M THE DEPUTY CHIEF OF STAFF

THE OFFICE OF PERSONNEL MANAGEMENT.

>> ARLENE PATEL, INTERNAL POLICY AND PROGRAM DIVISION ACTING
CHIEF IN THE OFFICE OF THE SECRETARY U.S. DEPARTMENT OF
TRANSPORTATION.

OF

>> ERIC BENSON, THE SENIOR ADVISOR TO THE DEPUTY SECRETARY

VETERAN'S AFFAIRS.

>> THANK YOU VERY MUCH.

MS. FORD?

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IMPORTANT

>> THANK YOU FOR THIS OPPORTUNITY TO TESTIFY ON THESE

ISSUES.

AND

THE ARC OF THE UNITED STATES HAS SUBMITTED WRITTEN COMMENTS

ENDORSED COMMENTS BY THE CONSORTIUM FOR CITIZENS WITH

OF

DISABILITIES AND THE NATIONAL ASSOCIATION OF STATE DIRECTORS

DEVELOPMENTAL DISABILITY SERVICES.

I WILL HIGHLIGHT JUST A FEW ISSUES TODAY.

HEALTH WE URGE HHS TO MOVE CAUTIOUSLY IN IMPLEMENTATION OF THE

INSURANCE FLEXIBILITY AND ACCOUNTABILITY DEMONSTRATION.

BELIEVE AS WE UNDER THE BREADTH OF THE WAIVERS ENVISIONED, WE

UNDERMINE THAT THE DEMONSTRATION HAS THE POTENTIAL TO COMPLETELY

THE NEW FREEDOM INITIATIVE.

OPTIONAL SPENDING COMPRISES 65% OF TOTAL MEDICAID SPENDING.

PEOPLE WITH DEVELOPMENTAL DISABILITIES RECEIVE PRIMARILY

MEDICAID OPTIONAL SERVICES FOR MOST OF THEIR LONG TIME CARE.

WE BELIEVE THAT THE STATE'S OBLIGATION TO THESE INDIVIDUALS,

INCLUDING APPROPRIATE, HIGH QUALITY, INDIVIDUALLY DESIGNED

LONG-TERM SERVICES MUST NOT BE DIMINISHED IN ANY WAY.

SERVICES EXTENSIVE WAIVERS COULD BE USED TO DIMINISH MANDATORY

FOR OPTIONAL POPULATIONS, SUCH AS THE EPSDT PROGRAM FOR CHILDREN.

BASED ON CERTAIN REQUIREMENTS OF MEDICAID LAW WERE PUT IN PLACE,

FAMILIES' AND CONSUMERS' NEGATIVE EXPERIENCES WITH STATE SERVICES PROGRAMS.

SUCH IMPORTANT PROTECTIONS SHOULD NOT BE ELIMINATED.

SECONDLY, I WANT TO EMPHASIS THE IMPORTANCE OF CMS' ROLE IN

SUPPORTS OVERSIGHT MONITORING AND QUALITY ASSURANCE OF LONG-TERM

AND SERVICES.

WE BELIEVE THAT THE ICFMR REGULATIONS NEED TO BE UPDATED TO COMPORT WITH THE STATE OF THE ART IN 2001 BY INCLUDING INDIVIDUAL PREFERENCES, CHOICES, AND SELF-DETERMINATION IN THE PROGRAM.

IN ADDITION, HHS MUST CONTINUE THE OVERSIGHT AND MONITORING OF THE ICFMR PROGRAM.

FOR THE HOME AND COMMUNITY-BASED WAIVER SERVICES PROGRAM, THE LARGEST AND MOST POPULAR PROGRAM PROVIDING THESE SERVICES, CMS MUST DEVISE REASONABLE AND EFFECTIVE APPROACHES TO ENSURE THAT THE STATES FULFILL THEIR QUALITY OVERSIGHT RESPONSIBILITIES. FURTHER, AS NEW APPROACHES ARE DEVELOPED, QUALITY ASSURANCE MECHANISMS MUST BE ESTABLISHED WITH CLEAR LINES OF RESPONSIBILITY.

OTHERWISE, WE RISK THE POSSIBILITY OF SERIOUS HEALTH AND SAFETY PROBLEMS IN COMMUNITY-BASED PROGRAMS.

A KEY ISSUE FOR QUALITY IS THE GROWING CRISIS IN THE DIRECT CARE WORK FORCE.

THE CRISIS IS THE RESULT OF FLAT APPROPRIATION, OFTEN FOR YEARS AT A TIME, FOR EXISTING PROGRAMS RESULTING IN AN INABILITY TO PAY DECENT LIVING WAGES AND BENEFITS TO DIRECT CARE WORKERS. THERE IS ENORMOUS VARIATION FOR THE SAME WORK PERFORMED BY STATE WORKERS VERSUS PRIVATE SECTOR WORKERS WHO ARE PAID SUBSTANTIALLY LESS.

THIS RESULTS IN HUGE TURNOVER, AND SUBSTANTIAL VACANCIES IN

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RISK
STAFF POSITIONS, PLACING PEOPLE LIVING IN THE COMMUNITY AT
THE
OF INSTITUTIONALIZATION AND DENYING THOSE WANTING TO LEAVE
INSTITUTIONS THE OPPORTUNITY TO DO SO.
THESE PROBLEMS PLAGUE SERVICE DELIVERY SYSTEMS DESIGNED TO
ARE
PROVIDE VERY PERSONAL SERVICES AND SUPPORTS TO PEOPLE WHO
OFTEN VERY VULNERABLE.
FAILURE TO ADDRESS THESE ISSUES IN A REAL WAY WILL ALSO
UNDERMINE EFFORTS OF THE NE FREEDOM INITIATIVE.
WE URGE HHS TO WORK CLOSELY WITH THE DEPARTMENT OF LABOR TO
STUDY THESE ISSUES AND IMPLEMENT EFFORTS TO BEGIN TO RESOLVE
THE
CRISIS.
AGAIN, WE BELIEVE THAT THE ADMINISTRATION'S PLACEMENT OF A
IMPORTANT
PRIORITY ON OLMSTEAD AND THE NEW FREEDOM INITIATIVE IS
AND CAN PRODUCE SIGNIFICANT GROWTH AND PROGRESS IN MEETING
PEOPLE'S NEEDS IN THEIR OWN COMMUNITIES.
WE URGE THE ADMINISTRATION TO SERIOUSLY ADDRESS THE ISSUES
NOT
RAISED TODAY, TO ENSURE THAT THESE IMPORTANT INITIATIVES ARE
DESTROYED BY OTHER FORCES.
FINALLY, WE URGE THE ADMINISTRATION TO SIGNIFICANTLY INVOLVE
DIRECTIONS.
CONSUMERS IN ALL OF THESE IMPORTANT DECISIONS AND
THANK YOU.
>> THANK YOU MS. WARD.

>> MR. MULTON?

>> THANK YOU.

MY NAME IS DENNIS MULTON.

AND I AM THE COFOUNDER AND PRESIDENT OF ENABLEMART.COM OUR

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COMPUTER MISSION IS TO ASSIST THE INDIVIDUALS IN THE SEARCH FOR
ACCESS AND COMPUTER ACCESS SOLUTIONS.
OUR VISION IS TO BRING ABOUT AWARENESS WITHIN THE COMMUNITY
AND TO INCREASE THE NUMBER OF INDIVIDUALS USING ASSISTIVE
TECHNOLOGIES, AND THUS PROVIDING A LINK TO THE BENEFITS OF
COMPUTER HARDWARE AND SOFTWARE.
AND MICROSOFT'S LONG STANDING VISION OF A COMPUTER ON EVERY DESK
IN EVERY HOME SHOULD ALSO BE AN INDUSTRY-WIDE CALLING TO
ACTION FOR MAKING COMPUTERS AND SOFTWARE ACCESSIBLE TO EVERYONE.
ACCORDING TO GOVERNMENT FIGURES, ONE PERSON IN FIVE HAS SOME
FUNCTIONAL LIMITATION.
AND 8% OF ALL THE USERS ON THE WEB HAVE SOME TYPE OF NEED
ENABLEMART CAN FILL.
CAN IN THE U.S. ALONE THERE ARE MORE THAN 30 MILLION PEOPLE WHO
WIDE, BE AFFECTED BY THE DESIGN OF COMPUTER SOFTWARE. AND WORLD
THE NUMBER IS MUCH HIGHER.
ALL PEOPLE WHO CAN BENEFIT FROM ASSISTIVE TECHNOLOGIES ARE IN
TRADES AND PROFESSIONS.

THEY ARE COMPUTER PROGRAMMERS, ENGINEERS, AND ACCOUNTANTS,
TEACHERS, OR RESEARCHERS, WHO ARE BLIND, DEAF, AND
PARAPLEGIC.

AS COMPUTERS BECOME CENTRAL TO MORE AREAS, INCREASING
NUMBERS OF

THESE INDIVIDUALS NEED TO USE COMPUTERS IN THEIR WORK AND
EDUCATION.

ADAPTABLE COMPUTER INTERFACES, ERGONOMIC KEYBOARDS, PORTABLE
THESE DEVICES, VOICE RECOGNITION, AND ARTIFICIAL SPEECH, ALL OF

WERE DEVELOPED FOR OR FIRST ADOPTED BY ASSISTIVE TECHNOLOGY

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MANUFACTURERS AND THEIR CUSTOMERS.

A THE TECHNOLOGY THAT IS BEING DEVELOPED TODAY TO ACCOMMODATE
VARIETY NUMBER OF NEEDS ARE THE FUTURE OF THE HIGH TECH
INDUSTRY.

AND ENABLEMART WILL BE THERE TO LOCATE AND SUPPORT IT.

AND IN CONCLUSION, I HAVE COME HERE TODAY TO STRESS ONE POINT

MAKE ONE REQUEST.

TECHNOLOGY IS KEY IN THE INCLUSION OF INDIVIDUALS WITH
DISABILITIES INTO TODAY'S FAST PACED TECHNOLOGY DEPENDENT
SOCIETY.

THE FINANCIAL SUPPORT, NOT TO MENTION AWARENESS, IS ESSENTIAL TO
PROCESS.

THIS WHILE IT IS OUR SOCIAL DUTY AND RESPONSIBILITY TO AID IN
MISSION, WE NEED MORE HELP.

FINANCIAL THE NEW FREEDOM INITIATIVE IS A GREAT START, BUT THE
DOLLARS AND CONSUMER AWARENESS ASPECTS, TO DATE, ARE FAR
BEHIND.
AS WE HAVE SEEN NEITHER.
HELP US ENABLE AMERICA WITH THE TOOLS TO LEAD MORE
INDEPENDENT LIVES.
THANK YOU.
>> THANK YOU.
MS. KANGAS?
>> THANK YOU.
MY NAME IS KAREN KANGAS.
I HAVE A MAJOR PSYCHIATRIC DISABILITY, A MOTHER WHO DIED
FROM MENTAL ILLNESS BECAUSE SHE WAS TOO EMBARRASSED TO GET HELP,
A
90
SISTER WHO PRESENTLY HAS MENTAL ILLNESS AND ALCOHOLISM.
SHE IS UNEMPLOYED AND POOR.
MY STRUGGLES TO MAINTAIN AND MANAGE MY MENTAL ILLNESS,
BIPOLAR DISORDER, IS DIFFICULT.
IT IS DEFINITELY NOT TREATED LIKE MY CARDIAC CONDITION.
I WAS FORTUNATE BEFORE MENTAL ILLNESS INVADED MY WORLD TO
COMPLETE MY FORMAL EDUCATION.
WAS EVEN WITH MY DEGREES, INCLUDING A DOCTORED IN EDUCATION, I
FIRED FROM MY CAREER, A PRINCIPAL OF AN ELEMENTARY SCHOOL.
I WAS IN THE HOSPITAL WHEN I WAS TOLD THAT I WOULD BE FIRED
FOLLOWING AN EPISODE.

THIS LEFT ME DEVASTATED, SOMETIMES HOMELESS, AND HOPELESS.
AND I WAS TOLD THAT I WOULD NEVER WORK AGAIN.

HELP
I FINALLY LANDED A JOB IN THE MENTAL HEALTH FIELD WITH THE
AS
OF THE OFFICE OF PROTECTION AND ADVOCACY WHERE I WAS KNOWN

THE MENTAL PATIENT WITH KEYS.

I WAS ONE OF THE FIRST HIRED AS A DISCLOSED CONSUMER.

I APPLAUD THE NEW FREEDOM INITIATIVE.

THIS IS EXCITING FOR MY FRIENDS LIVING WITH SERIOUS MENTAL
ILLNESS.

BAGS,
THE REALITIES OF LOCKED DOORS, RESTRAINTS, SECLUSION, BODY
NOT
HEAVY-DUTY FORCED MEDS STILL ARE A PART OF THEIR NIGHTMARES,

THEIR DREAMS, AND STILL EXISTS.

MANY FRIENDS ARE IN JAILS.

THE BARRIERS TO THE COMMUNITY ARE MANY.

BE
FOR MOST OF US, HOWEVER, THE GREATEST IS DISCRIMINATION, TO

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CRY,
LOCKED OUT BY COMMUNITY LIVING BY ATTITUDES OF PEOPLE WHO

BETTER
"I DON'T WANT CRAZY PEOPLE LIVING NEXT DOOR TO ME," "THEY

INVITED
NOT HIRE THEM, THEY ARE VIOLENT," "THEY'RE NOT CERTAINLY

TO MY HOUSE."

THERE
I LOOK FORWARD TO OUR NATIONAL ROLE MODELS TO HELP, BUT

ARE FEW OF THEM, FEW DISCLOSED PEOPLE WHO WANT TO FACE THESE

ATTITUDES.

SO WE DEAL WITH OUR INSIDE PAIN, DEPRESSION, RACING IDEAS,
INTRUSIVE THOUGHTS, ANXIETY, NIGHTS WITHOUT SLEEP.

LACK OF BUT WE NEED YOUR HELP TO DEAL WITH THE OUTSIDE PAIN, THE
JOBS, HOMES, EDUCATION, AND TRANSPORTATION.

PEOPLE WITH PSYCHIATRIC DISABILITIES NEED TO HAVE EXPANDED
SERVICES, WAIVERS UNDER MEDICAID, REHAB OPTIONS.

WE NEED NEW IMPROVED SERVICES.

TO OUR MEDICATIONS ARE SO EXPENSIVE, AND WE REALLY DON'T WANT
TAKE THEM.

IT IS EXTREMELY DIFFICULT TO LIVE.

BACK I HEAR PEOPLE SAY, I'M SORRY, KAREN, BUT I WOULD RATHER GO
TO THE INSTITUTION, IT'S EASIER.

AGENCIES EVEN THOUGH I WORK IN THE MENTAL HEALTH FIELD, I FIND
VERY FRAGMENTED.

I'M WAITING TO HELP MY SISTER WHO IS A THOUSAND MILES AWAY,
TRYING TO LOCATE A SECTION 8 VOUCHER.

SHE'S BEEN WAITING YEARS.

AND SHE WANTS SUPPORTED EDUCATION, TRANSPORTATION.

AND IT'S HARD TO FIGURE OUT WHERE SHE SHOULD GO, WHERE, WHEN,

OFTEN WHY.

THE NATIONAL COMMISSION ON MENTAL HEALTH BRINGS TEARS TO MY
EYES, TO THINK THAT MENTAL ILLNESS IS FINALLY ON THE
NATIONAL

AGENDA.

BLUE

THE SURGEON'S GENERAL REPORT, THE GOVERNOR IN CONNECTICUT'S

RIBBON COMMISSION, HAS BEEN ABSOLUTELY WONDERFUL.

LAST OF

BEING SOBER FOR THE MOST OF MY 15 YEARS, I AM NOW ON THE

MEDICATIONS APPROVED BY THE FDA FOR MY DISORDER.

THERE'S A BRIGHT LIGHT, HOWEVER.

MY ASSOCIATION WITH SAMHSA, ESPECIALLY CMHS AND THE CSP
PROGRAMS, ARE WONDERFUL ALSO.

BLOCK

THE MENTAL HEALTH BLOCK -- EXCUSE ME, THE MENTAL HEALTH

GRANTS HAVE BROUGHT NEW PROGRAMS THAT ARE CONSUMER-RUN.

ADDICTION

IN CONNECTICUT AT THE DEPARTMENT OF MENTAL HEALTH AND

SERVICES, WE HAVE USED A SMALL PORTION OF OUR BLOCK GRANT TO

AND

PARTNER WITH A TOP NOTCHED ADVERTISING FIRM PRO BONO TO PLAN

IMPLEMENT AN ANTI-STIGMA CAMPAIGN.

WE KNOW THAT EDUCATION IS ESSENTIAL, THEREFORE, WE HAVE
EDUCATIONAL MATERIALS AVAILABLE FOR SCHOOLS, LIBRARIES,
THEATERS, AND TELEVISION.

LIVE

OUR THEME IS, PEOPLE WITH MENTAL ILLNESSES DO RECOVER AND

PRODUCTIVE LIVES IN THE COMMUNITY.

PLEASE RESPECT US AND TREAT US THE SAME AS OTHER PEOPLE.

I URGE YOU TO HELP US.

TOGETHER WE CAN GET PEOPLE INTO TREATMENT AND CHANGE THE
HEADLINES FROM NEGATIVE TO POSITIVE.

WE NEED AGENCIES AND SERVICES THAT ARE INTEGRATED,
COORDINATED,
AND DESIGNED FOR PEOPLE WHOSE DISABILITIES RELAPSE, RETURN,
STABILIZE, AND WITH HELP AND HOPE, RECOVER.
THANK YOU FOR YOUR CONCERN.
>> THANK YOU, MS. KANGAS.
MS. WHITMAN.
>> I'M SUE WHITMAN, CO-CHAIR OF THE LONG-TERM CARE COMMITTEE
FOR
THE MAYOR'S HEALTH POLICY COUNCIL IN THE DISTRICT.
I WOULD LIKE TO TALK ABOUT OLDER PEOPLE, PARTICULARLY THE
VERY
OLD, 85 AND OLDER.
THERE WERE 4 MILLION OF THEM LAST YEAR.
END THEY'RE EXPECTED TO BE 5 1/2 MILLION BY THE YEAR 2010.
73% OF THE 4 MILLION NEED SOME ASSISTANCE.
IT OFTEN COMES AS A SHOCK TO THEM THAT MEDICARE DOES NOT PAY
FOR
LONG-TERM CARE.
THE FAMILY, THEY DISCOVER, PAYS, AND THE FAMILY PROVIDES THE
CARE.
THIS CARE IS WORTH BILLIONS TO FEDERAL AND STATE
GOVERNMENTS.
THERE'S SOMETHING WRONG WITH THE SYSTEM.
I THINK WHAT IS NEEDED IS FUNDING FOR OLDER PEOPLE WHICH
WILL
ENABLE THEM TO HIRE SOME PERSON FOR THEIR CARE, INCLUDING
FAMILY
MEMBERS OR NONPROFESSIONALS.
THE PARAPROFESSIONAL HOME CARE WORKERS ARE BECOMING VERY
HARD TO
FIND.

1997,

THE FEDERAL GOVERNMENT REDUCED PAYMENTS FOR HOME CARE IN
AND 30% OF THE AGENCIES WENT OUT OF BUSINESS.

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FURTHERMORE, IF YOU DO FIND A WORKER, HOME CARE WORKER, AND
YOU'RE PAYING FOR IT YOURSELF, YOU MAY BE PAYING \$15 TO \$22
AN
HOUR.

MANY FAMILIES CAN'T AFFORD THAT.

MIGHT
MEDICAID HELPS WITH HOME CARE FOR THE ELDERLY/POOR, WHO
OTHERWISE BE SENT OFF TO NURSING HOMES, BUT THE FEDERAL
GOVERNMENT APPROVES THIS EXPENDITURE THROUGH A VERY
COMPLICATED

WAIVER PROCESS, WHICH I WONDER WHY IS NECESSARY.

INTEGRATED
THE SUPREME COURT, IN THE OLMSTEAD DECISION, SAYS THE FRAIL
ELDERLY HAVE THE RIGHT TO RECEIVE CARE IN THE MOST
SETTING.

FOR
WHY THEN IS THERE A NEED TO APPEAL TO THE FEDERAL GOVERNMENT

THE PRIVILEGE OF PROVIDING THIS HOME CARE?

TERM
FOR THOSE IN THE MIDDLE CLASS FINANCIALLY, THERE IS NO LONG-
CARE OF ANY KIND FROM THE FEDERAL GOVERNMENT.

LAWYERS
THE MIDDLE CLASS, HOWEVER, SOMETIMES CAN AFFORD TO HIRE

POOR,
TO HELP THEM SPIN DOWN SO THAT THEY CAN DECLARE THEMSELVES

THUS AVOIDING PAYMENT OF \$60,000 OR MORE FOR A NURSING HOME.

THAN TO
THE RECOMMENDATIONS, IT'S EASIER TO DESCRIBE THE PROBLEM

FIND A SOLUTION.

WELFARE WE CANNOT CONTINUE, HOWEVER, TO DEPEND ON MEDICAID, A PROGRAM, TO MEET THE NEEDS OF THE SEVERELY DISABLED WITH THE MIDDLE CLASS PRETENDING TO BE POOR TO RECEIVE MEDICAID HELP. NOR CAN WE DEPEND ON FAMILIES TO PROVIDE LONG-TERM CARE. THE BABY BOOMERS MAY NOT BE UP TO IT. THE FAMILIES ARE DISBURSED.

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ARE IT'S NOT GOING TO BE EASY TO FIND FAMILIES IN THE FUTURE WHO GOING TO TAKE ON THIS RESPONSIBILITY. NOW, THIS WILL REQUIRE -- TO PROVIDE CARE IN THE HOME IS GOING TO COST THE COUNTRY MONEY, BUT OLDER AMERICAN ACT PROGRAMS, IN ADDITION, MUST BE ADEQUATELY FUNDED TO STRENGTHEN COMMUNITY SERVICES. SHOULD THE WAIVER PROCESS FOR HOME AND COMMUNITY-BASED SERVICES BE STREAMLINED OR ABOLISHED. SINGLE ENTRY POINTS SHOULD BE PROVIDED FOR THOSE SEEKING SERVICES. ADEQUATE SALARIES AND BENEFITS FOR HOME CARE WORKERS SHOULD BE AND LOW COST TRAINING FOR THOSE SEEKING HOME CARE JOBS. IN ALL OF THIS WILL COST MONEY, BUT WE'RE THE RICHEST COUNTRY THE WORLD. SURELY WE WILL BE ABLE TO FIND MONEY FOR THE AILING ELDERLY.

>> MS. WHITMAN, THANK YOU VERY MUCH.

MS. WHITMAN WAS THE LAST OF THE INDIVIDUALS TESTIFYING IN
THE

FIRST SEGMENT OF THE AGENDA, THE FIRST PUBLIC TESTIMONY
SEGMENT.

I WOULD LIKE TO THANK THE FOUR INDIVIDUALS HERE.

**To view the other parts of the listening session, click on the links
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